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Examination of Dementia Caregivers' Experiences: The
Role of Suffering and Empathy in the Caregiving
Relationship and a Review of the Evidence Base for
Interventions Targeting Caregiver Anxiety

Rebecca Slade

Doctorate in Clinical Psychology

The University of Edinburgh

August 2014

(Final Submission: July 2015)

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Acknowledgements

I would like to sincerely thank all of the couples that took time out of their already busy and complicated lives to participate in my study. Your openness and generosity were truly admirable and I felt honoured to be able to listen to your experiences with dementia and with caregiving.

I would also like to thank Emma Law and Phil Brown at the Scottish Dementia Clinical Research Network, as well as the clinicians in the Angus and Dundee Community Mental Health Teams, who were invaluable in supporting recruitment.

I would like to thank my supervisors, Dr Fiona Macleod, Professor Kevin Power and Dr David Gillanders, for their support and guidance throughout this project. This has undoubtedly helped the development of the project, as well as my own understanding of the processes involved in completing research. I also want to thank Professor Ken Laidlaw for his support in the initial process of shaping the focus of my research.

Finally, to my family, friends and Ryan, I cannot thank you enough for your endless understanding and moral support, as well as the provision of well-timed distractions during the last three years. I would like to dedicate this thesis to my mum.

Thesis Abstract

Background

Dementia, which affects an estimated 35 million individuals worldwide, is now recognised as a growing health and economic problem. With insufficient levels of health and welfare services in many nations, there exists a reliance on family caregivers to provide care for individuals with dementia (IWDs). However, the potential negative psychological and physical consequences of the caregiving role cannot be ignored. A growing literature base has improved the theoretical understanding of mental health difficulties (e.g. depression, burden) in caregivers. However, significant gaps in the research remain. These include understanding outcomes such as caregiver anxiety and examining the role of potentially crucial variables, such as levels of suffering and empathy.

Objectives

An empirical study was conducted in order to add to the literature regarding depression and anxiety in spousal caregivers of IWDs. This research conducted exploratory analyses of the relationships between the suffering of IWDs, IWDs' depression and anxiety, caregivers' levels of empathy, caregiver satisfaction and caregiver anxiety and depression. Caregivers' anxiety and depression is considered in the context of research on co-morbidity. In addition, the levels of discrepancy between ratings of suffering, whereby caregivers frequently report IWDs to be suffering more than IWDs self-report, were also examined. A systematic review was conducted in order to evaluate the effectiveness of psychosocial interventions for anxiety in informal caregivers of IWDs.

Method

For the empirical study, a cross-sectional survey methodology was employed where dyads of caregivers and IWDs completed questionnaires during face-to-face interviews. Primary variables examined were the suffering of IWDs, IWDs' levels of depression and

anxiety, and caregivers' levels of empathy, satisfaction, depression and anxiety. The suffering of IWDs was rated both by the IWDs (self-reported suffering) and the caregivers (perceived suffering). Descriptive statistics and exploratory correlational analyses were used to address a number of exploratory research questions regarding the relationships between the investigated variables. For the systematic review, five scientific databases were searched for relevant randomised controlled trials (RCT). Study quality was assessed according to standardised, recommended criteria and a qualitative synthesis of the evidence, including effect sizes, is described.

Results

Results from the empirical study suggest high levels of clinical anxiety in the caregiver population. In the current sample, there was a high prevalence rate of anxiety (52.5%) and a lower rate of depression (15.0%). However, there were no statistically significant correlates for caregiver anxiety and depression found. Findings are discussed in the context of previous research, the demographics of the current sample and difficulties with recruitment. For the systematic review, twenty studies with substantially different methodological quality were included. Anxiety was rarely identified as the primary outcome measure. However, the evidence suggests that Cognitive Behavioural skills training and psycho-educational interventions can be effective in treating caregiver anxiety. Some preliminary evidence for interventions underpinned by Mindfulness-based strategies was also found.

Conclusions

The empirical study found that a large proportion of Scottish spousal caregivers experience clinical levels of anxiety. This suggests that caregiver anxiety must be a key priority for both clinicians and researchers alike. In addition, further research examining these understudied variables and using dyadic methods remains crucial to increasing understanding into caregivers' outcomes. The systematic review demonstrated that research regarding interventions for anxiety in caregivers is growing and there is now a greater emphasis on the underlying theoretical models of delivered interventions. There

is also growing evidence that interventions with clear theoretical basis may be more likely to be effective. However, both the empirical study and the systematic review highlight further questions that remain to be addressed in the literature. Further research continues to be necessary in this area to ensure that services are appropriately meeting the needs of both caregivers and IWDs.

Content and Format

Chapter 1: The Systematic Review chapter is written in adherence of guidelines specified by *The International Journal of Geriatric Psychiatry*. References cited within this article are listed at the end of this chapter. Appendix A1, pages 112-117, displays the author guidelines for this journal.

Chapter 2: The Empirical Study chapter is written in adherence of guidelines specified by *The Journal of Psychology and Aging*. References cited within this article are listed at the end of this chapter. Appendix B1, pages 137-141, displays the author guidelines for this journal.

Chapter 3: The full Appendices for Chapters 1 and 2 are located in the third chapter. This contains all additional documents used in completing the systematic review and empirical study, where permitted by copyright laws.

Word Counts

Thesis Abstract: 604 words

Systematic Review (including abstract and tables): 8, 329 words

Journal Article (including abstract and tables): 9, 300 words

Total Thesis Portfolio: 18, 233 words

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List of Abbreviations

| | |
|---------|--|
| ACE-III | Addenbrooke's Cognitive Examination, Third Edition |
| AD | Alzheimer's Disease |
| BPS | British Psychological Society |
| BSI | Brief Symptom Inventory |
| CBT | Cognitive Behavioural Therapy |
| CMHT-OP | Community Mental Health Team – Older People |
| CRD | Centre for Reviews and Dissemination |
| CSS | Caregiving Satisfaction Scale |
| GHQ | General Health Questionnaire |
| HADS | Hospital Anxiety and Depression Scale |
| IRI | Interpersonal Reactivity Index |
| IWD | Individual with Dementia |
| MBSR | Mindfulness Based Stress Reduction |
| MCI | Mild Cognitive Impairment |
| MMSE | Mini Mental State Examination |
| NHS | National Health Service |
| RCT | Randomised Controlled Trial |
| SDCRN | Scottish Dementia Clinical Research Network |
| SIGN | Scottish Intercollegiate Guidelines Network |
| SIMD | Scottish Index of Multiple Deprivations |
| SPSS | Statistical Package for the Social Sciences |

SYSTEMATIC REVIEW

Title: *Psychosocial interventions to treat anxiety in caregivers of individuals with dementia: A systematic review of randomised controlled trials*

Running Title: *Psychosocial interventions to treat anxiety in caregivers of individuals with dementia*

Authors:

Rebecca Slade, Trainee Clinical Psychologist, Clinical Psychologist, School of Health in Social Science, University of Edinburgh

Fiona Macleod, Consultant Clinical Psychologist, Lead Clinician, NHS Tayside Older People Psychological Therapies Service

Kevin Power, Head of Service, NHS Tayside Psychological Therapies Service

David Gillanders, Senior Lecturer, School of Health in Social Science, University of Edinburgh

Corresponding Author: Rebecca Slade, Trainee Clinical Psychologist, The University of Edinburgh, Clinical Psychology, School of Health in Social Science, Medical School, Teviot Place, Edinburgh, EH8 9AG

Word count (excl. Abstract, Tables and References): 5, 181

Word count (excl. References): 8, 329

Prepared in accordance with the author guidelines for *The International Journal of Geriatric Psychiatry*.

Structured Abstract

Objective: To review evidence on psychosocial interventions for anxiety in informal caregivers of individuals with dementia. To synthesise evidence from published randomised controlled trials (RCT) and to assess methodological quality using standardised quality criteria. Finally, to appraise the theoretical models underlying delivered interventions.

Methods: A systematic literature search of five scientific databases was performed, covering literature published up to 01 March 2014. Study quality was assessed according to standardised, recommended criteria based on the Scottish Intercollegiate Guidelines Network (SIGN) and Centre for Reviews and Dissemination (CRD) guidelines. A qualitative synthesis of the evidence is described, with an emphasis on methodological quality, theoretical models and intervention effectiveness, as defined by effect sizes.

Results: Twenty studies met inclusion criteria. Seven papers found small to large effect sizes for caregiver anxiety following the delivered interventions. Treatment models of interventions included Cognitive Behavioural Therapy, reminiscence groups (e.g. Cognitive Stimulation Therapy) and Mindfulness-Based interventions. The Stress Process Model and the Stress and Coping Framework were also used to guide intervention development. However, methodological quality differed across studies, in particular with regards to allocation concealment, outcome blinding and sample sizes.

Conclusions: New evidence has emerged to suggest the effectiveness of Cognitive Behavioural skills training and psycho-educational interventions for anxiety in caregivers. There is also preliminary evidence to suggest that interventions that draw on Mindfulness-based strategies may also be effective in treating anxiety. It was found that interventions with a clear theoretical basis appear more likely to be effective.

KEY WORDS – Dementia; Caregiver; Anxiety

Introduction

Informal caregiving for individuals with dementia has consistently been shown to be positively associated with significant physical health, mental health and social consequences (e.g. Schulz *et al.*, 1995; Pinquart & Sorensen, 2003). Over the past 30 years, a proliferation of research has focused on interventions for these individuals. Systematic reviews and meta-analyses have explored the effectiveness of psychosocial, environmental and technological interventions (e.g. Brodaty *et al.*, 2003; Elvish *et al.*, 2013). Additional reviews have examined particular types of interventions (e.g. Chien *et al.*, 2011; Boots *et al.*, 2013) and outcomes in specific subgroups of caregivers (e.g. Thompson & Spilsbury, 1998). A number of caregiver outcomes have been investigated, including quality of life, burden, coping strategies, sense of self-efficacy and measures of psychological distress (e.g. anxiety and depression).

Although anxiety has been recognised to be prevalent in caregivers, it remains a relatively neglected research outcome in this population (Cooper *et al.*, 2007a). Evidence suggests that anxiety disorders may have similar or greater prevalence than depression in caregivers (Mahoney *et al.*, 2005; Russo *et al.*, 1995). It is estimated that approximately a quarter of caregivers present with clinically significant anxiety, however little research has explored relevant correlates (Cooper *et al.*, 2007b). Preliminary evidence suggests that past histories of depression and anxiety (Russo *et al.*, 1995), increased knowledge about dementia (Graham *et al.*, 1997) and female gender (Mahoney *et al.*, 2005) may be positively associated with anxiety in caregivers. Research also suggests that subjective physical health and quality of the relationship with the care recipient may be negatively associated with anxiety (Mahoney *et al.*, 2005).

Caregiver anxiety has also been recognised as an independent outcome that potentially requires targeted interventions (Schulz *et al.*, 2002). Nonetheless, many systematic reviews have often either excluded anxiety as an outcome or included relatively few papers that measure anxiety (Sorensen *et al.*, 2002; Schulz *et al.*, 2002; Selwood *et al.*,

2007).

One previous systematic review (Cooper *et al.*, 2007a) clearly highlighted the research regarding psychosocial interventions for caregiver anxiety. Twenty-four papers were included from a literature review conducted in June 2005, including 10 randomised controlled trials (RCT). Studies were graded by level of evidence according to the Centre for Evidence-Based Medicine guidelines. Evidence from RCTs and good quality cohort papers was discussed separately from studies with poorer grading. The authors noted the methodological limitations in the literature and the limited evidence for intervention efficacy. Preliminary evidence for relaxation techniques and yoga was highlighted. However, no clear analysis of the theoretical underpinnings of the delivered interventions was presented, despite the importance of this having been emphasised in previous literature (e.g. Knight *et al.*, 1993).

To the authors' knowledge, no other reviews to date have examined psychosocial interventions for caregiver anxiety and no such reviews have focused solely on RCTs or examined effect sizes. The present review therefore attempts to rectify these gaps in the literature by systemically reviewing the evidence from published RCT studies, using standardised quality assessment criteria and effect sizes. This will provide a synthesis of existing evidence from studies that employ the gold standard of research design. This will also include 10 recently published RCTs that have not previously been included in a review regarding caregiver anxiety. In order to amend another gap in the literature, a clear appraisal of the theoretical models underpinning interventions is also included.

Method

Search Strategy

In March 2014, MEDLINE R (1946 –), EMBASE (1947 –), PsycINFO (1806 –), Allied and Complementary Medicine (1985 –) and the British Nursing Index (1994 –) databases were searched using the terms 'carer' or 'caregiver', 'dementia' or 'Alzheimer's Disease' (AD) and 'anxiety'. This search strategy replicates the one used by Cooper *et al.* (2007a). The decision to replicate this approach was made following a

review of other relevant systematic reviews and consideration of other possible search terms. References of all included papers and relevant systematic reviews, as well as the related articles function in MEDLINE, were used to search for further relevant papers. The reviewer (RS) was not blinded to the names of authors, journals or institutions.

Selection Criteria

Papers that reported the effects of a psychosocial intervention on anxiety in informal caregivers of community-dwelling people with dementia were included. Psychosocial interventions were defined as any intervention that targeted psychological or social factors (Ruddy & House, 2005). This definition encompasses interventions that include psychological treatment, psycho-education and social support. Papers that included caregivers of individuals with diagnoses of Mild Cognitive Impairment (MCI) were included only where the majority of participating individuals cared for individuals with diagnoses of dementia. Anxiety had to be measured using validated quantitative outcome measures. Only randomised controlled trials (RCT) published in English were included. A trial was defined as an RCT if randomised allocation of participants to treatment and comparison groups was described. Papers that described pharmacological treatments of the caregiver, or care recipients' move into long-term care, were excluded. Dissertations were excluded. Papers were selected by one author (RS).

Data Extraction and Quality Assessment

Data extraction was performed by one author (RS) and can be found in Tables 1 – 4. Tables are organised based on the primary therapeutic (e.g. Cognitive Behavioural Therapy, Mindfulness-based, Reminiscence-based) or theoretical model (e.g. Stress & Coping) underlying the delivered interventions. These were identified based on the authors' descriptions of the interventions' development and treatment components delivered. Studies were organised in this manner to allow for clearer appraisal of the theoretical models underpinning interventions as suggested by previous authors (e.g. Knight *et al.*, 1993).

Tables 1–4 also provide an overview of the effect sizes of intervention outcomes for

anxiety. Recent authors have argued that p-values are not particularly informative in determining whether a statistically significant effect is clinically meaningful and substantive (Crutzen, 2010; Volker, 2006). However, effect sizes provide a better opportunity to quantify the intervention outcomes and were therefore examined in this review. As recommended by Morris (2008), effect sizes were based on the mean pre-post change in the treatment group minus the mean pre-post change in the control group, divided by the pooled pre-test standard deviation. This method has been found to obtain the most precise effect size estimate (Morris, 2008).

Where studies reported insufficient information to calculate effect sizes, authors were contacted and necessary data was provided in all but one case (Rabinowitz *et al.*, 2006). Two studies reported insufficient data to calculate effect sizes at follow-up time points (Akkerman *et al.*, 2004; Gendron, 1996), therefore data from these time points are not included in the review. In line with Cohen's classification (Cohen, 1988), effect sizes were divided into five levels: trivial (Cohen's $d \leq .2$), small ($> .2$), moderate ($> .5$), large ($> .8$), and very large (> 1.3).

The methodological quality of the studies was assessed using relevant and applicable quality criteria developed for this review. Twelve quality criteria were chosen based on the Scottish Intercollegiate Guidelines Network (SIGN) and Centre for Reviews and Dissemination (CRD) criteria. Criteria included assessment of the research questions, allocation concealment, blinding procedures, attrition rates, intention to treat analysis, sample size and discussion of limitations. Appendix A3 illustrates the full quality criteria checklist used. Each study was assessed by the author (RS) and an independent co-rater (KP or FM). Table 5 outlines the final quality ratings for the studies.

Results

Search Results

A total of 2,389 citations from the searched databases were identified. An additional four citations were identified through other methods such as reference screening. Based on abstracts, 147 papers were deemed to be potentially eligible for inclusion. Examination

of full-text versions resulted in 20 studies being included in this review (Tables 1– 4).

A flowchart diagram (Figure 1) details this selection process. Full details of the 20 papers are reported in Tables 1 – 4. Appendices A3 and A4 provide more detail regarding the excluded papers.

FIGURE 1: Flowchart Detailing Literature Search Process

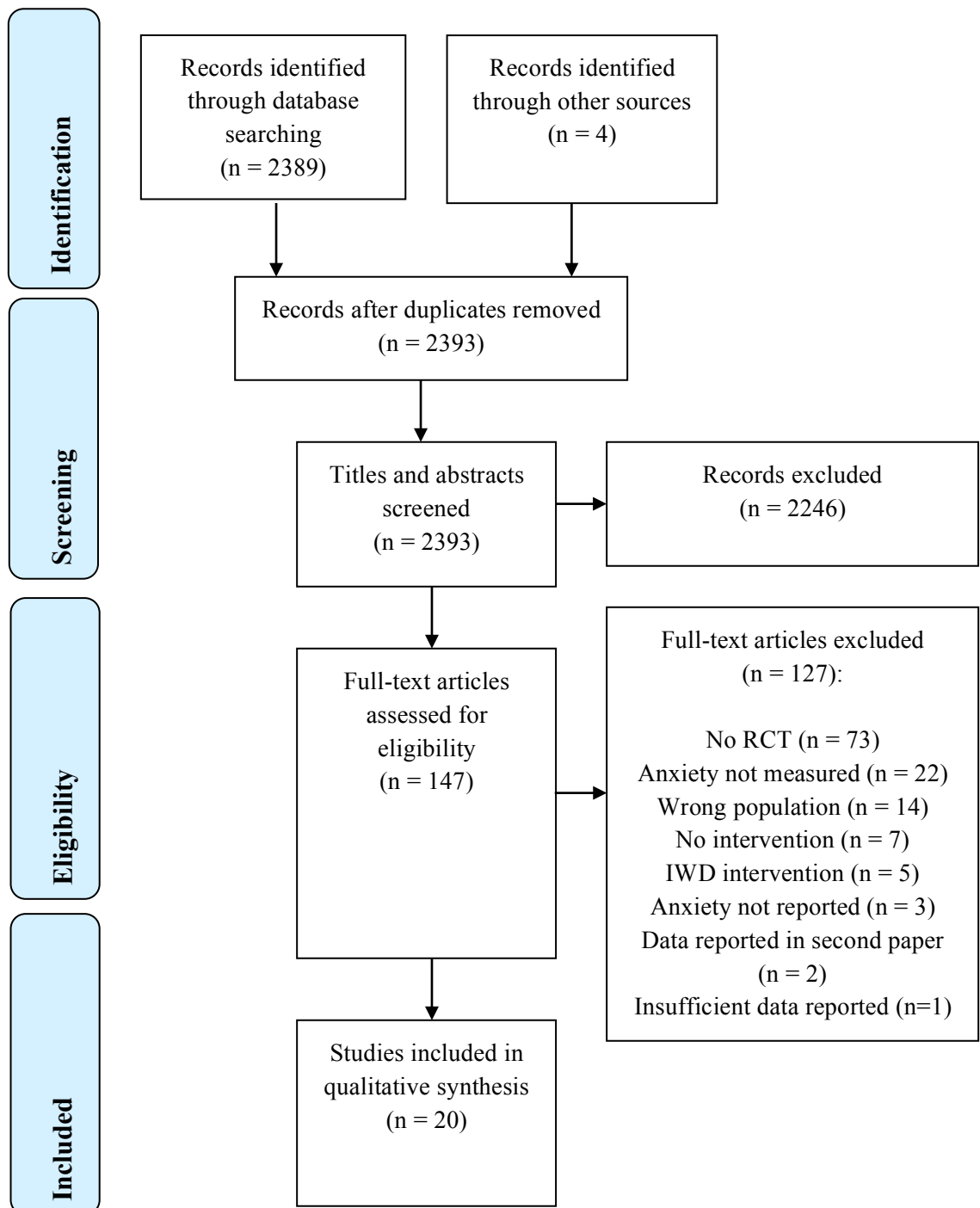


TABLE 1: Interventions Underpinned Primarily by Cognitive Behavioural Therapy models

| Authors, Year, Country | Participants | | Intervention | | | |
|--|---|----------|---|---|---|-------|
| | Age, sex & relationship where provided | <i>n</i> | Description | Outcome Measures | Effect Sizes for Measures of Anxiety (Cohen's d) | |
| <i>Cognitive and/or Behavioural interventions delivered individually</i> | | | | | | |
| Chang, 1999; United States | Female family caregivers of IWD, where the IWD presents with significant dressing and eating problems; mean age = 66.5 years; spouse (88.6%). | 34 | 1. Nurseline video-assisted modelling program (NVAMP): Videos showing assisted modelling behaviour (dressing/eating) and weekly telephone support for coping strategies and cognitive restructuring. 8 weeks. | BSI, WCS, CAT | Mid-intervention (at 4 weeks) | 0.07 |
| | | | | | Post-intervention | -0.21 |
| | | 31 | 2. Attention-Only control group: Weekly calls to assess caregiver well-being. No specific strategies offered. Matched for time and duration. | | 4 weeks follow-up | -0.03 |
| Judge <i>et al.</i> , 2012; United States | IWDs and their primary family caregivers; mean age = 65.4 years (range 27–87); female (73.7%); spouse (60.2%), non- spouse (39.8%). | 68 | 1. Acquiring New Skills While Enhancing Remaining Strengths (ANSWERS): Curriculum-guided sessions with caregiver and IWD. Psycho-education, staying active, communication strategies, managing memory and recognising emotions and behaviours. Worksheets and resource pack. 6 sessions of 90 minutes. | SAS, CES-D, CMS, CSS, PGS, DRS, SES, QOL- AD | Post-intervention | 0.25* |
| | | 60 | 2. Control Group: Standardised educational resource pack with information on dementia, treatments, home care and community agencies. | | | |
| Livingston <i>et al.</i> , 2013; United Kingdom | Primary family caregivers of IWD; mean age = 60.0 years (range 18–89); female (68.5%); partner (41.9%), child (43.5%), other (14.6%). | 173 | 1. Strategies for Relatives (START): Individual manualised CBT (based on “Coping with Caregiving”). Psycho-education, behavioural management, cognitive techniques, assertiveness, relaxation and skills maintenance. 8 sessions delivered over 8-14 weeks. | HADS, ZBI, MCTS, HSQ-12, COPE, CDRS, QOL-AD | Post-intervention | -0.02 |
| | | 87 | 2. Treatment as Usual (no attention placebo). | | 8 months from baseline | 0.00 |
| <i>Notes:</i> Strength of Effect size is denoted as follows in Tables 1 – 4: Trivial ($d \leq .2$) * = Small ($> .2$) ** = Moderate ($> .5$) *** = Large ($> .8$) **** = Very large (> 1.3) | | | | | | |

| <i>Cognitive and/or Behavioural interventions delivered in groups</i> | | | | | | |
|---|---|-----|---|--|--------------------------|--------------------------------|
| Akkerman <i>et al.</i> , 2004; United States | Family caregivers of individuals with AD; mean age = 58.1 years (range 34–85); female (86%). | 18 | 1. CBT group intervention: Involved didactic skills training (e.g. relaxation). 2 hours weekly for 9 weeks. | HAMA, BAI | Post-intervention (HAMA) | 1.01*** |
| | | 17 | 2. Waitlist control with no attention-placebo. | | Post-intervention (BAI) | 1.27*** |
| Gendron, 1996; Canada | Spousal caregivers of IWD; mean age = 66.2 years (range 46–83); female (65.7%). | 18 | 1. CBT skills training group: Problem solving, assertiveness and cognitive restructuring. Discussed Control group topics. 90-minute sessions weekly for 8 weeks. | HSC, RMPBC, ATQ, JCS, RAI, DAS, ZBI | Post-intervention | -0.36 |
| | | 17 | 2. Control: Group social support and information on health and aging, dementia, community resources, nutrition, respite and legal issues. Matched for time and duration. | | | |
| Hébert 2003; Canada | Primary caregivers of IWD; mean age = 59.7 years; female (80.5%); spouse (61.0%). | 79 | 1. CBT psycho-educational group: Cognitive appraisal (4 sessions) and coping strategies (11 sessions on problem solving, reframing and social support). 15 weekly 2-hour sessions. | STAI-20 (State), RMBPC, ZBI, BRAS, ISSB, IPSI | Post-intervention | -0.07 |
| | | 79 | 2. Control Group: Traditional support groups offered locally. | | | |
| Martín-Carrasco <i>et al.</i> , 2014; Spain | Informal caregivers of IWD; mean age = 62.1 years; female (77.3%); spouse/partner (49.1%), adult child (45.4%), other (5.5%). | 115 | 1. Psycho-education Intervention Program (PIP): Based on “Coping with Caregiving”. Psycho-education, cognitive and behavioural skills training, relaxation, communication skills and emotional control. 7 fortnightly 90-120 minute sessions. | GHQ-28, SF-12, ZBI | 4 months from baseline | 0.19 |
| | | 123 | 2. Treatment as Usual (no attention placebo). | | 8 months from baseline | -0.07 |
| Rabinowitz <i>et al.</i> , 2006; United States | Female family caregivers of individuals with AD/DR or recent MMSE \leq 23; mean age = 57.2 years; spouses (40.0%), other (60.0%). | 105 | 1. Coping with Caregiving Class (CWC): Skills-building group intervention. Cognitive behavioural mood management skills, relaxation and pleasant activities scheduling. 2 hours weekly for 10 weeks, then monthly for 8 months. | STAI-10, CES-D, ISSB, RWCC | Post-intervention | Insufficient data to calculate |
| | | 108 | 2. Enhanced Support Group: Guided discussion and empathic listening. Matched for time and duration | | | |

| Cognitive and/or Behavioural interventions delivered with group and individual components | | | | | | |
|---|--|----|--|--|---|-------|
| Bourgeois <i>et al.</i> , 2002; United States | Spousal caregivers of IWD; mean age = 72.6 years; female (54%). | 21 | 1. Self Change Group: 3 hour workshop on problem solving and relaxation. 1 hour weekly home sessions. 10 weeks. | STAI-20, SAES, Behave-AD, CSS, CSEA, PSS, CES-D, CHI | Intervention 1 vs 3 ¹ : Post-intervention | -0.51 |
| | | 22 | 2. Patient Change Group: Workshop on behavioural principles. Weekly home sessions. Matched for time and duration. | | 3 months follow-up | -0.57 |
| | | 20 | 3. Visitation Control Group: Support group meeting. Weekly home sessions (no skills training). Matched for time and duration. | | 6 months follow-up | -0.47 |
| | | | | | Intervention 2 vs 3 ¹ : Post-intervention | -0.22 |
| | | | | | 3 months follow-up | -0.33 |
| | | | | 6 months follow-up | -0.34 | |
| Burgio <i>et al.</i> , 2003; United States | White and African American family caregivers of IWD; mean age = 62.8 years; female (78%); spouses (50%), other (50%). | 70 | 1. Skills Training: 3 hour group workshop. 16 home treatment sessions. Behaviour management techniques, problem solving and cognitive restructuring. 12 months. | STAI-10, RMBPC, PAC, LSNI, LTS, CES-D | Mid-intervention (after 6 months): African-Americans | 0.21* |
| | | 70 | 2. Minimal Support Condition: Non-individualised telephone support (approximately 15 minutes length) on above schedule. Matched for duration. | | White Americans | -0.06 |
| Joling <i>et al.</i> , 2012; Netherlands | Informal primary caregivers of IWD; mean age = 69.5 years; female (67.5%); spouse (90.5%), non-spouse (9.5%). | 96 | 1. Family Meetings Intervention: 1 individual session, 4 family meetings and 1 final individual evaluation session. Psycho-education, problem solving and mobilising social support. 1 year (sessions held every 2-3 months). | HADS-A, CES-D, MINI, CRA, SF-12 | Mid-intervention (after 6 months) | 0.10 |
| | | 96 | 2. Treatment as Usual (no attention placebo). | | Post-intervention | 0.16 |
| | | | | | | |
| Mohide <i>et al.</i> , 1990; Canada | Dyads of co-habiting IWD (moderate to severe) and family caregivers; mean age = 67.8 years; female (71.5%); spouses (76.7%). | 30 | 1. Caregiver Support Program (CSP): Caregiver health assessments, education and behavioural management training. Monthly 2-hour caregiver support groups. 6-months with weekly home visits and 4-hour blocks of in-home respite. | STAI, CES-D, CQLI, CSASS | Mid-intervention (after 3 months) | 0.29* |
| | | 30 | 2. Conventional Community Nursing Care: Addressed physical needs of IWD only. Frequency of visits left to nurses' discretion. Matched for duration. | | Post-intervention | 0.20* |

Notes:

¹Only outcomes for State Anxiety reported here

| Study | Intervention | Sample Size (n) | Control | Outcome Measure | Effect Size (d) |
|---|---|-----------------|---|-----------------------|-------------------------|
| Beauchamp <i>et al.</i> , 2005; United States | Employed informal caregivers of IWD; mean age = 46.9 years (range 19–84); female (73%); spouses (7%), children (67%), other relative (23%), other (3%). | 150 | 1. <i>Caregiver's Friend</i> : Web-based multimedia intervention providing text material and videos. Individually-tailored following questionnaire. Three modules: knowledge, cognitive and behavioural skills, and affective learning. Duration: 30 days access. | STAI, CSI, PAC, CES-D | Post-intervention 0.29* |
| | | 149 | 2. Waitlist control (no attention-placebo). | | |

Notes: AD = Alzheimer's Disease; ADRD = Alzheimer's Disease or Related Dementia; ATQ = Automatic Thoughts Questionnaire; BAI = Beck Anxiety Inventory; BEHAVE-AD = Behavioural Pathology in Alzheimer's Disease; BRAS = Bradburn Revised Affective Scale; BSI = Brief Symptom Inventory; CAT = Caregiver Appraisal tool; CES-D = Center for Epidemiologic Studies-Depression; CDRS = Clinical Dementia Rating Scale; CHI = Caregiver Health Index; COPE = COPE inventory; CQLI = Caregiver Quality of Life Instrument; CRA = Caregiver Reaction Assessment; CSASS = Cantril Self-Anchoring Striving Scale; DRS = Dyadic Relationship Strain; CSEA = Caregiver Self-Efficacy Assessment; CSM = Caregiver Mastery Scale; CSS = Caregiver Strain Scale; DAS = Dyadic Adjustment Scale; GHQ = General Health Questionnaire; HADS = Hospital Anxiety and Depression Scale; HAMA = Hamilton Anxiety Scale; HSC = Hopkins Symptom Checklist; HSQ = Health Status Questionnaire; IPSI = Ilfeld Psychiatric Symptoms Index; ISSB = Inventory of Socially Supportive Behaviours; IWD = Individual with Dementia; JCS = Jalowiec Coping Scale; LSNI = Lubben Social Network Index; LTS = Leisure Time Satisfaction; MCTS = Modified Conflicts Tactics Scale; MINI = Mini International Neuropsychiatric Interview; MMSE = Mini Mental State Examination; PAC = Positive Aspects of Caregiving; PGS = Personal Gains Scale; PSS = Perceived Stress Scale; QOL-AD = Quality of Life Alzheimer's Disease Scale; RAI = Rathus Assertion Inventory; RMBPC = Revised Memory and Behaviour Problem Checklist; RWCCCL = Revised Ways of Coping Checklist; SAES = Spielberger Anger Expression Scale; SAS = Zung Self-Rated Anxiety Scale; SES = Self Esteem Scale; SF-12 = Short Form Health-Related Quality of Life; STAI = State-Trait Anxiety Inventory; WCS = Ways of Coping Scale; ZBI = Zarit Burden Inventory.

TABLE 2: Interventions Underpinned by other Therapeutic Models

| Authors, Year, Country | Participants | | Intervention | | | |
|--|---|----------|--|--|---------------------------------------|---------|
| | Age, sex & relationship where provided | <i>n</i> | Description | Outcome Measures | Outcomes (for measures of anxiety) | |
| <i>Mindfulness-based interventions delivered with group and individual components</i> | | | | | | |
| Danucalov <i>et al.</i> , 2013; Brazil | Family caregivers of individuals with AD; mean age = 54.5 years; female (89%). | 25 | 1. Hatha Yoga and compassion meditation: Included yoga poses, breathing, mindfulness and compassion meditation. 75 minutes (3x/week: 1 live and 2 at home) for 2 months. | BAI , BDI, LSSI | Post-intervention | 1.10*** |
| | | 21 | 2. Waitlist control (no attention-placebo). | | | |
| Whitebird <i>et al.</i> , 2012; United States | Primary family caregivers of IWD; mean age = 56.8 years (range 32–82); female (88.5%); adult child = 74.4%, spouse/sibling/ friend = 25.6%. | 38 | 1. Mindfulness Based Stress Reduction (MBSR): Teaching mindfulness, meditation and Hatha yoga. Daily home practice. 150-minute group sessions and a 5-hour retreat. 8 week then 4 monthly telephone calls. | STAI , PSS, CES-D, SF-12, MBCBS, MOSSSS | Mid-intervention (after 2 months) | 0.01 |
| | | 40 | 2. Caregiver Education and Social Support (CCES): Psycho-education, community resources and self-care, and social support. Matched for time and duration. | | Post-intervention | -0.07 |
| <i>Cognitive Stimulation Therapy (CST) and Reminiscence interventions delivered in groups</i> | | | | | | |
| Woods <i>et al.</i> , 2012; United Kingdom | Dyads of IWD (mild to moderate) and informal caregivers; mean age = 77.5 years (range 23–91); female (67.0%); spouse (70.8%). | 268 | 1. Joint reminiscence groups: Manualised group intervention with participant dyads using themed reminiscence. Duration: 12 consecutive weekly sessions, then 7 monthly maintenance sessions. | GHQ-28 , HADS , QOL-AD, RSS, CSRI, BADLS, AMI, EQ, RAID,CSD, QCPR. | Mid-intervention (after 3 months) | -0.10 |
| | | 220 | 2. Treatment as Usual (no attention placebo). | | Post-intervention | -0.24 |
| <i>Notes:</i> AD = Alzheimer’s Disease; AMI = Autobiographical Memory Interview; BADLS = Bristol Activities of Daily Living Scale; BAI = Beck Anxiety Inventory; BDI = Beck Depression Inventory; CES-D = Center for Epidemiologic Studies-Depression; CSD = Cornell Scale for Depression in Dementia; CSRI = Client Services Receipt Inventory; EQ = European Quality of Life; GHQ = General Health Questionnaire; HADS = Hospital Anxiety and Depression Scale; IWD = Individual with Dementia; LSSI = Lipp’s Stress Symptoms Inventory for Adults; MBCBS = Montgomery Borgatta Caregiver Burden Scale; MOSSSS = Medical Outcomes Study Social Support Survey; PSS =Perceived Stress Scale; QCPR = Quality of the Carer-Patient Relationship; QOL-AD = Quality of Life Alzheimer’s Disease Scale; RAID = Rating Anxiety in Dementia; RSS = Relative’s Stress Scale; SF-12 = Short Form Health-Related Quality of Life; STAI = State-Trait Anxiety Inventory. | | | | | | |

TABLE 3: Interventions Underpinned by Theoretical Models

| Authors, Year, Country | Participants | | Intervention | | | |
|---|--|----------|---|---|--|-------|
| | Age, sex & relationship where provided | <i>n</i> | Description | Outcome Measures | Outcomes (for measures of anxiety) | |
| <i>Interventions Based on Social and Cognitive Theories</i> | | | | | | |
| Castro <i>et al.</i> , 2002; United States | Female family caregivers of IWD; mean age = 62.7 years (range 49–82); spouse (53%), adult child (47%). | 51 | 1. Moderate-intensity exercise training (individual): Introductory 30-40 minute session. Instructed to engage in 30 minute exercise sessions 4x/week. Weekly telephone contact (average of 15 minutes long) for 3 weeks, fortnightly for 1 month, then monthly for rest of the year (total of 15 contacts). Duration: 12 months. | TMAS , SCB, BDI, PSS, ISEL | Post-intervention | -0.38 |
| | | 49 | 2. Attention control group: Telephone-based nutrition education program. Matched for time and duration. | | | |
| <i>Interventions Based on Stress Process Theory</i> | | | | | | |
| Mahoney <i>et al.</i> , 2003; United States | Family caregivers of individuals with AD; mean age = 62.0 years; female (78%); spouse (54%), child (38%), sibling (5%), other (3%). | 49 | 1. Computer-mediated automated interactive voice response (IVR) (delivered individually): Weekly stress monitoring and information, personal voice-mail linkage to AD expert, voice-mail telephone support group and distraction calls for IWD. Duration: 12 months. | STAI-10 , CES-D, CMS, RMBPC | Mid-intervention (after 6 months) | 0.12 |
| | | | | | Post-intervention | 0.07 |
| | | 51 | 2. Control group: Reference booklet, with similar content to intervention Module 1 (behavioural management). | | 6 months follow-up | 0.25* |
| Burgio <i>et al.</i> , 2003; United States | See Table 1 for full details | | | | <u>Mid-intervention</u> African-Americans | 0.21* |
| | | | | | White Americans | -0.05 |
| Judge <i>et al.</i> , 2012; United States | See Table 1 for full details | | | | Post-intervention | 0.25* |
| Whitebird <i>et al.</i> , 2012; United States | See Table 2 for full details | | | | Mid-intervention (after 2 months) | 0.01 |
| | | | | | Post-intervention | -0.07 |

| <i>Interventions Based on Stress & Coping Framework</i> | | | |
|---|------------------------------|----------------------------------|-------|
| Chang, 1999; United States | See Table 1 for full details | Mid-intervention (at 4 weeks) | 0.07 |
| | | Post-intervention | -0.21 |
| | | 4 weeks follow-up | -0.03 |
| Hébert, 2003; Canada | See Table 1 for full details | Post-intervention | -0.07 |
| Beauchamp <i>et al.</i> , 2005; United States | See Table 1 for full details | Post-intervention | 0.29* |
| <i>Notes:</i> AD = Alzheimer's Disease; BDI = Beck Depression Inventory; CES-D = Center for Epidemiologic Studies-Depression; CMS = Caregiver Mastery Scale; ISEL = Interpersonal Social Evaluation List; IWD = Individual with Dementia; PSS = Perceived Stress Scale; RMBPC = Revised Memory and Behaviour Problem Checklist; SCB = Screen for Caregiving Burden; STAI = State-Trait Anxiety Inventory; TMAS = Taylor Manifest Anxiety Scale. | | | |

TABLE 4: Interventions Without Clear Theoretical Basis

| Authors, Year, Country | Participants | | Intervention | | | |
|--|---|----------|---|---|---|-------|
| | Age, sex & relationship where provided | <i>n</i> | Description | Outcome Measures | Outcomes (for measures of anxiety) | |
| <i>Social Support interventions</i> | | | | | | |
| Charlesworth <i>et al.</i> , 2008; United Kingdom | Family caregivers of IWD; mean age = 68.0 years; female (64%); spouse (67%), non-spouse (33%). | 116 | 1. BECCA (Befriending and costs of caring) Social Support: Voluntary sector based intervention providing emotional support and limited informational support. Minimum duration of 6 months. | HADS-A , HADS-D, EuroQoL, PANAS, MSPSS | Post-intervention | 0.05 |
| | | | | | 9 months follow-up | 0.13 |
| | | | | | 18 months follow-up | 0.00 |
| | | 120 | 2. Treatment as Usual (no attention-placebo). | | | |
| <i>In-home Respite interventions</i> | | | | | | |
| Grant <i>et al.</i> , 2003; United States. | Spousal caregivers of individuals with AD; mean age = 73.3; female (61.9%). Vulnerability classified by hours of caregiving | 32 | 1. In home respite: In-home help who attended to the needs of the individual with dementia. Caregivers given choice of leaving the home or staying. 10 days (up to 6 hours per day) over a 2 week period. | HAMA , HAM-D, BSI-GSI | <u>Post-intervention:</u> Vulnerable group | 0.11 |
| | | | | | Non-vulnerable group | -0.02 |
| | | | | | | |
| | | 23 | 2. Treatment as Usual (no attention placebo). | | | |
| <i>Notes:</i> AD = Alzheimer’s Disease; BSI-GSI = Brief Symptom Inventory – Global Severity Index; EuroQoL = Health related quality of life; HADS = Hospital Anxiety and Depression Scale; HAMA = Hamilton Anxiety Scale; HAM-D = Hamilton Rating Scale for Depression; IWD = Individual with Dementia; MSPSS = Multidimensional scale of perceived social support; PANAS = Positive and Negative Affectivity Scale. | | | | | | |

TABLE 5: Methodological Quality Indicators for the Included Studies

| | Akkerman (2004) | Beauchamp (2005) | Bourgeois (2002) | Burgio (2003) | Castro (2002) | Chang (1999) | Charlesworth (2008) | Danucalov (2013) | Gendron (1996) | Grant (2003) |
|------------------------------|--------------------|---------------------|---------------------|------------------|------------------|-----------------|------------------------|---------------------|-------------------|-----------------|
| 1. Study Rationale | +++ | +++ | +++ | +++ | ++ | +++ | + | ++ | + | ++ |
| 2. Theoretical Framework | +++ | +++ | ++ | ++ | + | ++ | - | +++ | ++ | ++ |
| 3. Sampling Strategy | ++ | + | ++ | +++ | +++ | ++ | ++ | ++ | + | + |
| 4. Comparison Group | + | + | ++ | ++ | ++ | ++ | ++ | + | ++ | + |
| 5. Attrition Rates | ++ | +++ | ++ | +++ | +++ | +++ | +++ | +++ | +++ | - |
| 6. Allocation Concealment | + | + | +++ | ++ | ++ | + | ++ | + | + | + |
| 7. Outcome Blinding | ++ | +++ | ++ | - | - | - | ++ | - | ++ | - |
| 8. Intervention Delivery | ++ | +++ | +++ | +++ | ++ | + | + | ++ | ++ | + |
| 9. Outcome Description | +++ | ++ | ++ | ++ | ++ | + | + | ++ | + | + |
| 10. Data Analysis | - | - | - | +++ | - | - | - | - | +++ | - |
| 11. Sample Size | + | ++ | + | + | + | + | +++ | + | + | + |
| 12. Limitations Described | ++ | ++ | + | ++ | +++ | ++ | ++ | + | + | + |
| Overall Quality | 22 (61%) | 24 (67%) | 23 (64%) | 26 (72%) | 21 (58%) | 18 (50%) | 19 (53%) | 18 (50%) | 20 (56%) | 11 (31%) |

Scoring Guide:

Well-covered: 3 points (+++)

Adequately addressed: 2 points (++)

Poorly addressed: 1 point (+)

Not addressed or not described: 0 points (-)

| | Hébert (2003) | Joling (2012) | Judge (2013) | Livingston (2013) | Mahoney (2003) | Martin-Carrasco (2014) | Mohide (1990) | Rabinowitz (2006) | Whitebird (2013) | Woods (2012) |
|------------------------------|------------------|------------------|-----------------|----------------------|-------------------|---------------------------|------------------|----------------------|---------------------|-----------------|
| 1. Study Rationale | +++ | +++ | +++ | ++ | +++ | +++ | + | +++ | +++ | +++ |
| 2. Theoretical Framework | +++ | + | ++ | + | +++ | + | + | ++ | +++ | ++ |
| 3. Sampling Strategy | +++ | +++ | ++ | ++ | +++ | ++ | +++ | ++ | +++ | +++ |
| 4. Comparison Group | +++ | ++ | ++ | ++ | +++ | ++ | ++ | +++ | + | +++ |
| 5. Attrition Rates | +++ | +++ | + | +++ | +++ | ++ | ++ | +++ | +++ | ++ |
| 6. Allocation Concealment | ++ | +++ | + | ++ | ++ | +++ | ++ | + | ++ | +++ |
| 7. Outcome Blinding | +++ | ++ | ++ | + | ++ | ++ | ++ | + | - | +++ |
| 8. Intervention Delivery | +++ | ++ | +++ | +++ | +++ | ++ | ++ | +++ | ++ | +++ |
| 9. Outcome Description | ++ | ++ | + | ++ | ++ | ++ | ++ | ++ | ++ | +++ |
| 10. Data Analysis | ++ | +++ | - | - | - | +++ | - | +++ | +++ | +++ |
| 11. Sample Size | ++ | +++ | + | +++ | ++ | +++ | ++ | ++ | ++ | +++ |
| 12. Limitations Described | + | ++ | +++ | ++ | ++ | ++ | + | ++ | ++ | +++ |
| Overall Quality | 30 (83%) | 29 (81%) | 21 (58%) | 23 (64%) | 28 (78%) | 27 (75%) | 20 (56%) | 27 (75%) | 26 (72%) | 34 (94%) |

Scoring Guide:

Well-covered: 3 points (+++)

Adequately addressed: 2 points (++)

Poorly addressed: 1 point (+)

Not addressed or not described: 0 points (-)

Quality Assessment

Randomised allocation methodology and descriptions varied across papers. Thirteen papers reported the allocation concealment method used (Burgio *et al.*, 2003; Castro *et al.*, 2002; Charlesworth *et al.*, 2008; Grant *et al.*, 2003; Hébert, 2003; Livingston *et al.*, 2013; Mahoney *et al.*, 2003; Mohide *et al.*, 1990; Whitebird *et al.*, 2012) however only four papers described this method in full (Bourgeois *et al.*, 2002; Joling *et al.*, 2012; Martín-Carrasco *et al.*, 2014; Woods *et al.*, 2012). Blinding procedures at outcome assessment were described in eleven papers (Akkerman *et al.*, 2004; Beauchamp *et al.*, 2005; Bourgeois *et al.*, 2002; Charlesworth *et al.*, 2008; Gendron, 1996; Hébert, 2003; Joling *et al.*, 2012; Judge *et al.*, 2012; Mahoney *et al.*, 2003; Martín-Carrasco *et al.*, 2014; Mohide *et al.*, 1990; Woods *et al.*, 2012). Eight studies described both allocation concealment and blinding methods (Bourgeois *et al.*, 2002; Charlesworth *et al.*, 2008; Hébert, 2003; Joling *et al.*, 2012; Mahoney *et al.*, 2003; Martín-Carrasco *et al.*, 2014; Mohide *et al.*, 1990; Woods *et al.*, 2012).

Intention to treat analysis was explicitly described and used in seven papers (Burgio *et al.*, 2003; Gendron, 1996; Joling *et al.*, 2012; Martín-Carrasco *et al.*, 2014; Rabinowitz *et al.*, 2006; Whitebird *et al.*, 2012; Woods *et al.*, 2012). The intention to treat analysis was reportedly not completed in two papers due to missing baseline data (Charlesworth *et al.*, 2008) and missing data at follow-up points (Livingston *et al.*, 2013). Twelve papers described how missing data was handled. Methods used were casewise deletion (Beauchamp *et al.*, 2005; Bourgeois *et al.*, 2002; Burgio *et al.*, 2003; Castro *et al.*, 2002; Judge *et al.*, 2012; Livingston *et al.*, 2013), data imputation using means (Charlesworth *et al.*, 2008), chained equations (Joling *et al.*, 2012; Martín-Carrasco *et al.*, 2014), last value carried forward (Rabinowitz *et al.*, 2006) and estimates of model parameters (Whitebird *et al.*, 2012; Woods *et al.*, 2012).

Sample sizes varied widely across studies ($n = 35 - 488$), with most studies conducted with small or medium-sized samples. Attrition rates at the end of the treatment phase also varied and ranged from 7.7 per cent to 32.3 per cent. As well as voluntary drop-outs, reported reasons for attrition included institutionalisation of the IWD or caregiver,

death of the IWD or caregiver, and the participant no longer acting as the primary caregiver. One study did not report rates of attrition (Grant *et al.*, 2003). The low sample sizes and high attrition rates in some papers raises the question of adequate statistical power. A priori sample size calculations were described in only seven papers (Charlesworth *et al.*, 2008; Hébert, 2003; Joling *et al.*, 2012; Livingston *et al.*, 2013; Martín-Carrasco *et al.*, 2014; Whitebird *et al.*, 2012; Woods *et al.*, 2012). Two papers (Charlesworth *et al.*, 2008; Livingston *et al.*, 2013) estimated required sample sizes using total scores on the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). However, no studies calculated sample size using predicted effect sizes for anxiety as an independent outcome.

Nine papers investigated both the initial and longer-term effects of interventions, using follow-up assessments at delayed time points, in addition to immediate post-intervention assessment. These delayed follow-up assessments were completed between two to eighteen months following the end of the intervention (Bourgeois *et al.*, 2002; Charlesworth *et al.*, 2008; Chang, 1999; Gendron, 1996; Livingston *et al.*, 2013; Mahoney *et al.*, 2003; Martín-Carrasco *et al.*, 2014; Mohide *et al.*, 1990; Whitebird *et al.*, 2012). Follow-up assessments at delayed time intervals could provide further information regarding the long-term impact of the interventions on caregiver anxiety. However, due to studies not using intention to treat analysis (Bourgeois *et al.*, 2002; Chang, 1999; Charlesworth *et al.*, 2008; Livingston *et al.*, 2013; Mohide *et al.*, 1990) and lower retention rates at delayed assessment points (e.g. 60.5% at 4 months post-intervention in Martín-Carrasco *et al.*, 2014), the long-term impact of these interventions remains difficult to assess.

Monitoring of treatment fidelity was described in 10 papers (Akkerman *et al.*, 2004; Beauchamp *et al.*, 2005; Bourgeois *et al.*, 2002; Burgio *et al.*, 2003; Hébert, 2003; Joling *et al.*, 2012; Judge *et al.*, 2012; Livingston *et al.*, 2013; Rabinowitz *et al.*, 2006; Woods *et al.*, 2012). Methods included the use of treatment protocol manuals, supervision throughout treatment delivery and audio recordings being graded for treatment fidelity. These procedures are imperative as, without the establishment of treatment integrity,

conclusions regarding treatment efficacy cannot be reached with confidence (Burgio *et al.*, 2001; Yeaton & Sechrest, 1981).

Theoretical Underpinnings of Interventions

Studies made use of a number of therapeutic treatment models including traditional Cognitive Behavioural Therapy (CBT), Reminiscence-based groups (e.g. Cognitive Stimulation Therapy) and Mindfulness-Based Therapies.

As can be seen in Table 1, 13 papers described interventions based on CBT (Akkerman *et al.*, 2004; Beauchamp *et al.*, 2005; Bourgeois *et al.*, 2002; Burgio *et al.*, 2003; Chang, 1999; Gendron, 1996; Hébert, 2003; Joling *et al.*, 2012; Judge *et al.*, 2012; Livingston *et al.*, 2013; Martín-Carrasco *et al.*, 2014; Mohide *et al.*, 1990; Rabinowitz *et al.*, 2006). These treatments were aimed at providing caregivers with strategies to challenge negative thought processes and to alter unhelpful response patterns. In some interventions, behavioural management strategies were also included. As indicated in Table 1, intervention delivery varied substantially and included treatments being delivered individually, in groups, via IT, or with a variety of components. A number of papers (e.g. Akkerman *et al.*, 2004; Beauchamp *et al.*, 2005; Gendron, 1996; Hébert, 2003) outlined the rationale for examining the chosen outcomes (e.g. anxiety, burden, automatic thoughts, social support, etc.) and demonstrated a clear link between theory and hypothesised effects. However, the rationale, in light of previous literature, for using the employed CBT techniques with a caregiver sample remained unclear in other papers (e.g. Bourgeois *et al.*, 2002; Burgio *et al.*, 2003; Chang, 1999; Joling *et al.*, 2012; Judge *et al.*, 2012; Mohide *et al.*, 1990).

Three further papers seen in Table 1 (Livingston *et al.*, 2013; Martín-Carrasco *et al.*, 2014; Rabinowitz *et al.*, 2006) delivered either the original “Coping with Caregiving” intervention developed for the Resources for Enhancing Alzheimer’s Caregivers Health (REACH; Schulz *et al.*, 2003) project or an intervention closely based on this treatment. This intervention is grounded in cognitive and behavioural principles that delineate the impact of thoughts and behaviours on negative affect (Beck *et al.*, 1979; Lewinsohn *et*

al., 1982). Through a psycho-educational group or delivered individually, the intervention aims to teach participants mood-management strategies to reduce the stress of caregiving and to manage caregiver distress (Wisniewski *et al.*, 2003). As the underlying theories of the intervention are described elsewhere, they are understandably not described in detail in these papers. However, there is also little description of the theoretical rationale for the selection of the outcomes variables (e.g. anxiety, depression, burden, quality of life) and mediators (e.g. self-efficacy) investigated.

Table 2 illustrates 3 papers that implemented other therapeutic models. Mindfulness Based Stress Reduction (MBSR) and more generic Mindfulness-Based interventions were examined in two papers (Danucalov *et al.*, 2013; Whitebird *et al.*, 2012). In these papers, a clear link was made between this model of intervention, the caregiver population and the chosen outcomes (e.g. anxiety, depression, stress, burden, quality of life). Another study in Table 2 (Woods *et al.*, 2012) examined the impact of joint reminiscence groups that included care recipient and caregiver dyads. A clear description of the research on reminiscence groups is described with some reference to the suggested impact on caregivers. Nonetheless, the authors do not clearly describe the rationale for choosing the investigated outcome measures (i.e. health well-being, depression, anxiety, caregiver-patient relationship) in light of this research. At post-intervention, intervention group caregivers demonstrated a reported significant increase in anxiety levels. In the past, similar unintended results have been hypothesised to potentially occur as a result of outcomes not being chosen with clear consideration of the specific predicted effects of the intervention (Knight *et al.*, 1993).

Table 3 includes eight papers that used existing theoretical models as the basis for the development and evaluation of their interventions. It should be noted that a number of these papers also implemented CBT or mindfulness models and were therefore also included in Tables 1 or 2. The Stress and Coping Framework (Lazarus & Folkman, 1984; Folkman *et al.*, 1991; Folkman, 2001) provided the foundation for three papers (Beauchamp *et al.*, 2005; Chang, 1999; Hébert, 2003). This model hypothesises that primary and secondary appraisals of stress mediate the negative relationship between

stressors and psychological outcomes. In caregivers, primary appraisals are the perception of the how stressful the caregiving role is. Secondary appraisals are the assessment of one's ability to cope, taking into account available resources and support. The objectives of these papers centred on improving appraisals through the teaching of cognitive strategies and coping skills. An explicit link between the model, the delivered intervention and the hypothesised outcomes is described. In spite of this, only Beauchamp *et al.* (2005) found a small effect size for anxiety. Hebert (2003) only found significant decreases in the frequency of, and reaction to, behavioural problems in the care recipient. This suggests that in some cases the intervention can result in a significant effect on primary but not secondary appraisals.

The Stress Process Model (SPM; Pearlin *et al.*, 1990) guided the development of interventions in four further papers (Burgio *et al.*, 2003; Judge *et al.*, 2012; Mahoney *et al.*, 2003; Whitebird *et al.*, 2012). SPM considers four domains in the development of dementia caregivers' stress. These include background and context variables (e.g. caregiving relationship), primary and secondary stressors (e.g. cognitive status and problematic behaviour of the care recipient, impact on caregiver's social life), mediators of stress (e.g. mastery, self-esteem, coping) and caregiver outcomes (e.g. anxiety, depression). Two papers (Judge *et al.*, 2012; Mahoney *et al.*, 2003) clearly described the model's influence on intervention development and research hypotheses also indicated clear links with the model's domains. Although these papers demonstrated small effect sizes on anxiety, Mahoney *et al.* (2003) reported a significant reduction at post-intervention was only found in those with low baseline mastery, indicating the relevance of the mediator domain in the model. In addition, Burgio *et al.*'s (2003) application of this model indicated that ethnicity or culture may be a potential mediator, as a small effect size was found only in African-American participants.

Notably, two studies (Charlesworth *et al.*, 2008; Grant *et al.*, 2003) made no direct reference to the theory or model underlying the investigated intervention. This small number of studies with limited theoretical description suggests an increased emphasis on delivering theoretically-based interventions in this population, particularly following

Cooper *et al.*'s (2007a) systematic review.

Effects of Interventions on Anxiety

Examination of effect sizes indicates that seven of the 20 papers demonstrated at least small effect sizes on caregiver anxiety at one or more recorded time points (Akkerman *et al.*, 2004; Beauchamp *et al.*, 2005; Burgio *et al.*, 2003; Danucalov *et al.*, 2013; Judge *et al.*, 2012; Mahoney *et al.*, 2003; Mohide *et al.*, 1990). All papers found small effect sizes, with the exception of two (Akkerman *et al.*, 2004; Danucalov *et al.*, 2013) which found large effect sizes. Notably, three of the seven papers were published subsequent to Cooper *et al.*'s (2007a) systematic review, indicating an increase in the evidence base for effective interventions. In addition, three papers (Burgio *et al.*, 2003; Mahoney *et al.*, 2003; Mohide *et al.*, 1990) that were reported to show non-significant effects on anxiety in Cooper *et al.*'s (2007a) review when examining *p* values were found to demonstrate small effect sizes. It therefore appears that examination of effect sizes does indicate different results. An additional paper (Rabinowitz *et al.*, 2006) reported significant reductions ($p = 0.014$) post-intervention, however effect sizes could not be calculated due to insufficient data.

Of the seven papers identified above, four found small or large effect sizes at post-intervention (Akkerman *et al.*, 2004; Beauchamp *et al.*, 2005; Danucalov *et al.*, 2013; Judge *et al.*, 2012). Mohide *et al.* (1990) found small effect sizes at post-intervention and mid-intervention time points. It should be noted that the effect size was smaller at post-intervention ($d = 0.20$) than at mid-intervention ($d = 0.29$). In comparison, Mahoney *et al.* (2003) results indicate trivial effect sizes at mid-intervention ($d = 0.12$) and post-intervention ($d = 0.07$), although there was a small effect size at follow-up ($d = 0.25$). These results suggest that interventions may differ in effectiveness across time points in delivery and further investigation is required to draw clearer conclusions.

Interventions demonstrating small to large effect sizes included CBT skills training and psycho-education in individual, group or multimedia formats (Akkerman *et al.*, 2004; Beauchamp *et al.*, Burgio *et al.*, 2003; Judge *et al.*, 2012; Mohide *et al.*, 1990),

automated telephone-based information and support provision based on Stress Process Theory (Mahoney *et al.*, 2003), and yogic meditation interventions (Danucalov *et al.*, 2013). At present, the most evidence for effectiveness exists for interventions offering CBT skills training and psycho-education. However, it must also be noted that 13 of 20 studies examined were underpinned by the CBT model. This indicates inconsistency in the results for CBT interventions, similar to the inconsistency across studies underpinned by other models identified in this review. This may indicate that the current method of classifying the underpinning model of interventions does not delineate between models adequately, or may be as a result of effectiveness being predicted by additional intervention or methodological factors. It should be noted however that both studies without theoretical underpinnings (Charlesworth *et al.*, 2008; Grant *et al.*, 2003) showed trivial effect sizes.

An additional factor that may impact on intervention effectiveness is the role of mediating variables. Two papers explored the role of mediating variables in changes in caregiver anxiety. Preliminary evidence from reported significance levels indicated that low baseline mastery (Mahoney *et al.*, 2003) and low baseline self-efficacy for obtaining respite (Rabinowitz *et al.*, 2006) may be relevant mediators. Effect sizes for these could not be calculated using the available data. As highlighted above, it was also found that effect sizes for Burgio *et al.*'s (2003) study varied across ethnicity, suggesting that race or potential cultural differences may also be relevant mediators. These variables may therefore be relevant when assessing the appropriateness of referrals to caregiver intervention programmes.

A number of methodological choices may also have impacted on the effect sizes found across studies. Methodological factors examined by authors included choice of control condition, length of treatment and structure of treatment. Three of the seven papers that reported small to large effect sizes employed waitlist control conditions (Akkerman *et al.*, 2004; Beauchamp *et al.*, 2005; Danucalov *et al.*, 2013) and an additional two (Judge *et al.*, 2012; Mahoney *et al.*, 2003) included control conditions with written information only. However, there were little evidence for a consistent pattern between the choice of

control groups and intervention effectiveness. Treatment duration spanned between 6 – 18 sessions, distributed over one month to one year. Interventions with small to large effect sizes varied across this full range. Five interventions (Akkerman *et al.*, 2004; Burgio *et al.*, 2003; Danucalov *et al.*, 2013; Judge *et al.*, 2012; Mohide *et al.*, 1990) with non-trivial effect sizes were delivered through regular structured sessions, suggesting that structured consistency may be helpful. However, two further studies (Beauchamp *et al.*, 2005; Mahoney *et al.*, 2003;) offered a less structured approach, where caregivers were given a specified timescale for treatment within which they could independently access the intervention at their own pace.

Another methodological factor that must be considered is the sample size recruited for the study. Of the seven studies found to have small to large effect sizes for anxiety, none included sample size calculations that suggested that they had sufficient power to accurately detect a difference in anxiety levels. In particular, the two studies that found large effect sizes both used relatively small sample sizes of 17 to 25 caregivers per group. Although this indicates that the effect was large enough to be found even within small sample sizes, it does mean that further research would be necessary to ensure these effects are generalisable.

Overall the quality of studies' methodology also varied widely (see Table 5). This must also be taken into consideration when making conclusions about the effectiveness of interventions.

Discussion

This review sought to rectify gaps in the existing literature by synthesising evidence from published RCTs on interventions for caregiver anxiety. Notably, a further 10 RCTs published between 2005 and 2014 were identified, in addition to the 10 RCTs previously reviewed by Cooper and colleagues (2007a). Unlike previous reviews, only RCTs were included, in order to synthesise evidence from studies with a higher standard of methodology. In addition, authors calculated effect sizes to examine treatment effectiveness.

A striking finding was that although further research has been published since Cooper and colleagues' (2007) review, a number of the same methodological limitations are still present. No further published RCTs have identified anxiety as an independent primary outcome measure since Akkerman and colleagues' (2004) paper. Anxiety is either measured as a secondary outcome, within a cluster of wider mental health well-being outcomes (e.g. depression, stress and burden), or within a sub-scale of a wider primary outcome measure (e.g. HADS, BSI or GHQ). Interventions that specifically target anxiety remain an understudied area. Given the high prevalence rates of anxiety within the caregiver population (e.g. Mahoney *et al.*, 2005), this gap in the literature therefore continues to be a significant barrier to offering evidence-based interventions to caregivers.

Another methodological weakness that limits the drawing of conclusions is the description of sample populations. Early authors in the literature emphasised the need to consider the inclusion and exclusion criteria used in this area of research (Knight *et al.*, 1993; Toseland & Rossiter, 1989). Existing evidence suggests that differences in gender and kinship relationship can result in variations in caregiving experiences (e.g. Etters *et al.*, 2008). Recommendations are that different interventions should be developed and offered to these different caregiver groups independently. Where this is not possible, it has been suggested that outcome data is reported separately for these groups, to enable examination of differential treatment effects (Knight *et al.*, 1993). Further evidence also suggests the utility of classifying caregivers on the basis of the care recipient's stage of dementia (Knight & Macofsky-Urban, 1990; Gallagher & Coon, 2007) and the type of dementia (Donaldson *et al.*, 1997). However, only eight papers adopted this approach to inclusion criteria. Examples of more limited inclusion criteria included females only (Chang, 1999; Castro *et al.*, 2002; Rabinowitz *et al.*, 2006), spouses/partners only (Bourgeois *et al.*, 2002; Gendron, 1996; Grant *et al.*, 2003) and caregivers of individuals with Alzheimer's disease only (Danucalov *et al.*, 2013; Mahoney *et al.*, 2003).

Quality assessment of the 20 RCT studies also highlighted continued limitations in the description and implementation of randomised allocation concealment, outcome

blinding and intention to treat analyses. In addition, there was variability in the reporting of sample size calculations. The monitoring of treatment integrity and fidelity appears to have improved within the more recent papers. However, the description of these procedures remains limited in many cases. The biases that these methodological shortcomings can cause must therefore be considered.

The link between theory and practice has previously been identified as a crucial and necessary feature in caregiving intervention research (Knight *et al.*, 1993). An examination of the theoretical underpinnings of interventions in the studies suggests that it is now more common for the development and evaluation of interventions to be grounded in theory. Although previous reviews highlighted an omission of theoretical models (Knight *et al.*, 1993; Carradice *et al.*, 2003), all but two studies either clearly described underlying theories or directed readers towards relevant literature.

In Cooper and colleagues' (2007a) review, the authors concluded that there was some preliminary evidence that group interventions that included yoga and relaxation without CBT were effective. They found a lack of evidence for behavioural management, exercise therapies and respite. Since their review was completed, three further RCTs have been published which provide evidence for the significant effects of interventions on caregiver anxiety. In addition, three RCTs have been found to have small effect sizes which were previously identified to have non-significant effects on anxiety in Cooper *et al.*'s (2007a) review. This therefore offers the opportunity for a revised interpretation of the existing evidence for interventions for caregiver anxiety.

The studies examined in the present review now provide a growing body of evidence for the effectiveness of Cognitive Behavioural skills training and psycho-educational interventions (Akkerman *et al.*, 2004; Beauchamp *et al.*, 2005; Judge *et al.*, 2012; Mahoney *et al.*, 2003). In addition, one study (Danucalov *et al.*, 2013) examining the application of Mindfulness-Based Stress Reduction (MBSR) also provides some initial evidence for the benefits of this approach. However, these findings remain preliminary due to the methodological weaknesses of the studies discussed above.

Examining those interventions that were effective, it was found that these were delivered in a range of formats, including individual, group and multi-media approaches. From the current evidence, it appears that interventions are more effective where theory clearly underpins the development and evaluation of delivered interventions. This positive association was found not only for Cognitive Behavioural Therapy and MBSR interventions, but also for the interventions based on the Stress Process Model and the Stress and Coping Framework. However, it should be noted that not all papers with clear theoretical basis demonstrated significant effects on anxiety. It may be that further theoretical understanding of caregiver anxiety continues to be needed in order to improve the development of delivered interventions.

As discussed above, the interventions reported in these studies were not developed solely to treat caregiver anxiety. Nonetheless, significant effects in reducing anxiety were found. This suggests that the specific strategies required to reduce caregiver anxiety may already be included within the content of interventions for other clinical outcomes (e.g. depression or burden). Clinically, this has important implications. It suggests that it may be possible to treat co-morbidity in this population with structured interventions that target several clinical outcomes concurrently. In future research, it may be beneficial for researchers to utilise a component analysis approach on interventions to identify which treatment components are most beneficial for clinical outcomes. Greater detail in the caregiver intervention research regarding the included therapeutic components may also aid in identifying those that are most positively associated with clinical change.

Conclusions

The evidence base for caregiver interventions that specifically target anxiety remains very limited. There continues to be a lack of homogeneity across studies, in particular regarding inclusion criteria, methodology, intervention formats and effect sizes. There is now stronger evidence that interventions that use Cognitive Behavioural skills training and psycho-education delivered within individual, group and multi-media formats can be effective in reducing anxiety in this population. In addition, there is preliminary

evidence to suggest that interventions that draw on Mindfulness-based strategies may also be effective. These results have been found despite these interventions not having been developed to specifically target anxiety. However, findings are not consistent across studies and therefore more rigorous research in this area continues to be needed. Close links between theoretical models, and intervention development and evaluation, are often apparent in the description of effective treatments. However, further RCTs continue to be needed to clarify which subgroups of caregivers are most likely to benefit from these interventions and to identify which therapeutic components are most likely to target caregiver anxiety in particular.

Conflicts of Interest

None

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EMPIRICAL STUDY

Title: A Dyadic Perspective of Caregiving: Exploring suffering, empathy, satisfaction and mental health outcomes among spousal caregivers of individuals with dementia

Running Title: Exploring suffering, empathy, satisfaction and mental health outcomes among spousal caregivers of individuals with dementia

Authors:

Rebecca Slade, Trainee Clinical Psychologist, Clinical Psychologist, School of Health in Social Science, University of Edinburgh

Fiona Macleod, Consultant Clinical Psychologist, Lead Clinician, NHS Tayside Older People Psychological Therapies Service

Kevin Power, Head of Service, NHS Tayside Psychological Therapies Service

David Gillanders, Senior Lecturer, School of Health in Social Science, University of Edinburgh

Corresponding Author: Rebecca Slade, Trainee Clinical Psychologist, The University of Edinburgh, Clinical Psychology, School of Health in Social Science, Medical School, Teviot Place, Edinburgh, EH8 9AG

Word count (excl. Abstract, Tables and References): 7, 993

Word count (excl. References): 9, 300

Prepared in accordance with the author guidelines for *Psychology and Aging*.

Abstract

The witnessing of distress and suffering in individuals with dementia (IWDs) has been identified as a potential source of negative psychological outcomes in caregivers. Although anxiety has been found to be prevalent in caregivers, it remains a relatively neglected outcome. This exploratory study aims to identify correlates of caregiver depression and anxiety, taking into consideration the co-morbidity often found between these. A cross-sectional study was conducted with 41 dyads of IWDs and their spousal caregivers. In separate interviews, caregivers were asked to rate the suffering of the IWD and IWDs were asked provide self-ratings using the same structured measures. Caregivers also completed measures of anxiety, depression, satisfaction and empathy, and IWDs completed anxiety and depression measures. Exploratory correlational analyses examined the relationships between variables. Authors aimed to identify any correlates of caregiver anxiety and depression, and to examine discrepancies in suffering ratings. Strikingly, a significant proportion of the caregivers (53.7%) presented with clinical levels of anxiety. A smaller proportion (17.1%) presented with clinical levels of depression. However, there were no statistically significant correlates for caregiver anxiety or depression found, except for a significant correlation indicating their co-morbidity. These findings highlight the necessary inclusion of anxiety as a primary psychological outcome in caregiver research, and the clinical need to increase successful identification and treatment of anxiety. Findings are discussed in the context of previous research, the demographics of the current sample and difficulties with recruitment. Further research examining these understudied variables and using dyadic methods remains crucial to understanding caregivers' outcomes.

Key Words: Suffering, Dementia, Caregiving, Anxiety, Depression

Introduction

Dementia caregiving is now recognised to be associated with a number of negative consequences for the psychological and physical well-being of informal family caregivers (e.g., Schulz *et al.*, 1995; Pinquart & Sorensen, 2006). Clinical observation and empirical investigations have demonstrated that these caregivers often experience high levels of burden, impaired self-care, poor quality of life, physical health difficulties, premature death, and restrictions in their personal, social and work lives (Schulz *et al.*, 1995; Gilleard *et al.*, 1984; Vitaliano *et al.*, 2003; Pinquart & Sorenson, 2003a, 2003b, 2007; Schulz & Beach, 1999).

A substantial literature has indicated that caregiving is also associated with increased psychiatric comorbidity (e.g. Donaldson *et al.*, 1998; Schulz *et al.*, 1995). Up to 46% of caregivers have been shown to have significant psychiatric symptomatology (Draper *et al.*, 1992). Further evidence suggests increased prescribed drug use among caregivers compared to non-caregivers (Schulz *et al.*, 1995). Depression, the most commonly researched mental health outcome in caregivers of individuals with dementia (IWDs), has an estimated prevalence rate of 22.3% (Cuijpers, 2005). Studies investigating anxiety report prevalence rates ranging from 3.7% to 76.5% depending on the methodology and sampling used. A recent systematic review suggests that it is likely that approximately a quarter of caregivers experience clinically significant anxiety (Cooper *et al.*, 2007a). Therefore, both anxiety and depression can be seen to be prevalent outcomes in this population.

The research regarding the predictors of anxiety and effective interventions for caregiver anxiety remains limited (Cooper *et al.*, 2007a; 2007b). It has been found that particular coping styles are related to caregiver anxiety. Other covariates such as burden and poor physical health, have been found to be related to both caregiver anxiety and depression (Cooper *et al.*, 2007a). Existing literature points to the considerable co-morbidity between anxiety and depression in caregivers of IWD. In one study (García-Alberca *et al.*, 2012) a positive correlation of .87 was found between anxiety and depression in

caregivers. Most caregivers with depression have also been found to also present with anxiety, however there is not always evidence for the contrary (Mahoney *et al.*, 2005; Molyneux *et al.*, 2008; García-Alberca *et al.*, 2012). Although the theoretical basis for this co-morbidity remains to be identified, research within the general elderly population suggests that the comorbidity between anxiety and depression is also prevalent out with the caregiver population. For example, Beekman and colleagues (2000) found that 47.5% of those with depression met criteria for an anxiety disorder, although only 26.1% of those with anxiety met criteria for co-morbid depression.

Within existing literature on caregivers of IWDs, the above negative outcomes, including anxiety and depression, have often been linked to primary stressors. These include the functional and cognitive impairments of the IWD, the presence of behavioural difficulties, the duration of the caregiving role and the associated caregiving demands (e.g. Schulz & Sherwood, 2008; Pinquart & Sorenson, 2003b; Steinmatz, 1988; Teri *et al.*, 1992). Associations between the negative consequences and secondary stressors (e.g. financial difficulties and relationship conflicts) have also been explored (e.g. Archbold, 1983; Fauth *et al.*, 2012). Demographic variables, such as caregivers' age, sex and relationship to the IWD (i.e. spouse, adult child or sibling), have been implicated in increased levels of stress and lower ratings of subjective well-being (e.g. Clyburn *et al.*, 2000; Yates *et al.*, 1999). In addition, variables such as caregivers' degree of spirituality (Rathier *et al.*, 2013), coping strategies (Haley *et al.*, 1996), personal and social resources (Lawton *et al.*, 1989a) and locus of control (Miller *et al.*, 1995) have been found to be significant mediators in the development of negative sequelae.

Suffering

Recently, researchers have explored the impact that witnessing the distress and suffering of an IWD may have on caregivers (e.g. Schulz *et al.*, 2008; Monin & Schulz, 2009; Day & Anderson, 2011). This area of research developed following literature that suggests that caregivers are vigilant to the physical and emotional distress of their loved ones. For

example, a number of studies indicate significant positive associations between the psychological distress of IWDs and the emotional experiences of caregivers (e.g. Hatfield, *et al.*, 1994; 2008; Keltner & Kring, 1998). Research evaluating the impact of psychological interventions for depression in IWDs has also shown that decreased depressive symptomatology in care recipients is associated with a decrease in depression and burden in caregivers (Teri *et al.*, 1997). Suffering can therefore be suggested as being experienced within an interpersonal context (Monin & Schulz, 2009).

In 2008, Schulz and colleagues highlighted that there was a lack of research on the independent effect of caregivers' perceptions of suffering in IWDs (herein referred to as perceived suffering) on caregivers' well-being. The authors emphasised the importance of exploring perceived suffering as a potential source of caregiver distress, independent of the primary and secondary stressors associated with providing care (Schulz *et al.*, 2008; 2013). They defined suffering as a holistic construct that encompasses three dimensions: physical symptoms, psychological distress and existential/spiritual distress (Monin & Schulz, 2009). The physical dimension measures symptoms such as pain, nausea and fatigue. Negative emotional states (e.g. anger, depression, fear) experienced by the IWD are measured within the psychological dimension. Finally, the existential suffering dimension is used to measure the level of meaning, purpose and peacefulness the IWD experiences (Schulz *et al.*, 2008).

To improve research in this area, a psychometric tool to quantitatively measure the three dimensions of suffering was developed. This tool was constructed so that it could be completed by caregivers to measure perceived suffering of IWDs or completed by IWDs to measure their self-reported levels of experienced suffering (Schulz *et al.*, 2010). It has previously been determined from interviewer ratings, Mini Mental State Examination (MMSE; Folstein *et al.*, 2001) scores and an analysis of measure responses that individuals scoring above 15 on the MMSE are able to provide reliable responses on this measure (Schulz *et al.*, 2013).

Initial research indicated important links between levels of perceived suffering and caregivers' psychological outcomes. Positive associations were also found between the levels of suffering self-reported by the IWD (herein referred to as self-reported suffering) and caregivers' psychological symptomatology. Using caregiver depression as an outcome variable, perceived levels of psychological and existential suffering were both found to independently contribute to caregiver depression. In longitudinal analyses, it was demonstrated that increases over time in the perceived levels of psychological and existential suffering were independently associated with increased levels of caregiver depression (Schulz *et al.*, 2008).

A later study (Schulz *et al.*, 2013), focused on a consistent finding that caregivers report IWDs as experiencing poorer health-related quality of life than IWDs self-report (e.g. Novella *et al.*, 2006; Sands *et al.*, 2004). Using the suffering measures, caregivers were shown to perceive IWDs as experiencing significantly higher levels of suffering and lower levels of quality of life than IWDs self-reported. Furthermore, there was a consistent positive association between the degree of discrepancy in the ratings, and caregiver depression and burden. Therefore, caregivers that rated perceived suffering higher than IWDs' self-reported suffering, experienced greater burden and were more likely to be depressed. Additional literature has identified other variables that contribute to this negative bias, including the type of domain being rated (i.e. subjective state or an observable behaviour), depressive symptomatology in the IWD and the IWD's level of cognitive impairment (e.g. Logsdon *et al.*, 2002; Novella *et al.*, 2001). The authors emphasised the need for further research to examine the development, maintenance and impact of this negative bias, as well as to more clearly delineate the impact of factors such as diagnosis type, gender and the relationship between the IWD and caregiver (Schulz *et al.*, 2013).

Consistent with the majority of caregiver literature, these studies did not explore caregiver anxiety as either an outcome measure or as an independent variable related to the negative bias. As a result, it is currently unknown how caregiver anxiety may relate

to the perceived suffering of IWDs. However, given the high levels of co-morbidity highlighted above, it is possible that suffering may also be related to caregiver anxiety.

Compassion Fatigue and Empathy

The research investigating the impact of perceived suffering on caregivers links well to the concept of compassion fatigue. Compassion fatigue was initially introduced in the literature as a specific form of burnout experienced by professional carers, with a particular focus on emergency care and oncology nurses (Joinson, 1992). It conceptualises an acute onset of negative emotional reactions (e.g. helplessness, hopelessness, isolation and an inability to be empathic) as a consequence of a caring relationship with suffering and/or traumatised individuals. Existing evidence demonstrates that professional compassion fatigue is also associated with increased levels of both depression and anxiety (Hegney *et al.*, 2014). Within the context of caregivers of IWDs, similar negative emotional reactions (e.g. burden, depression, anxiety) are hypothesised to occur in informal familial caregivers as a result of witnessing the suffering of the IWDs (Day & Anderson, 2011).

Empathic ability and empathic responses are understood to be important variables within the compassion fatigue process (Figley, 2002). Empathy has been conceptualised as a multi-dimensional variable that encompasses two central factors: cognitive empathy and affective empathy (Davis, 1983). Cognitive empathy is described as an intellectual approach to understanding the perspective of another and encompasses two dimensions (i.e. Fantasy and Perspective Taking). Affective empathy is also measured using two dimensions (i.e. Empathic Concern and Personal Distress) and encompasses the instinctual emotional reactivity of individuals (Davis, 1983). Within professional caregivers, a positive predictive relationship has been found between affective empathy measures, and compassion fatigue and personal distress. In contrast, higher levels of cognitive empathy have been shown to be associated with lower levels of compassion fatigue (Robins *et al.*, 2009).

Researchers have suggested compassion fatigue may be a relevant concept within caregivers of IWDs and have developed conceptual models that include caregiver compassion, anxiety and depression (Schulz *et al.*, 2007). Nonetheless, there remains a lack of empirical evidence for these models (Lynch & Lobo, 2012; Day & Anderson, 2011). This may be because there are no psychometric measures to specifically assess empathy or compassion fatigue in the caregiver population. However, measures of empathy that have been standardised with wider populations do exist (e.g. Interpersonal Reactivity Index; IRI, Davis 1980). To the authors' knowledge, no published papers to date have administered these empathy measures to a sample of caregivers.

Caregiver Satisfaction

The primary and secondary stressors discussed above, the witnessing of suffering and the potential experience of compassion fatigue within caregivers, provide multiple hypotheses regarding the development of negative outcomes (e.g. anxiety and depression) in caregivers of IWDs. However, the documented experience of perceived subjective benefits and personal growth (i.e. over and above the absence of pathology) that can result from caregiving must also be acknowledged (see Kramer, 1997). These gains may be a source of resilience that buffer against negative outcomes (Lopez *et al.*, 2005; Garity, 1997). For example, caregivers' ability to identify meaning or positive aspects of caregiving has been found to be associated with lower levels of burden, decreased experience of depression and greater subjective well-being (Cohen *et al.*, 2002). In addition, previous research has indicated small negative associations between caregiver satisfaction, and caregiver depression and anxiety (Lopez *et al.*, 2005). This evidence is consistent with models of compassion fatigue, which implicate a sense of satisfaction and/or meaning as a protective factor, buffering against the development of compassion fatigue and its associated psychological consequences (Day & Anderson, 2011).

Objectives of the Present Study

The present study sought to expand on the above findings by examining a number of exploratory hypotheses regarding the variables of suffering, empathy, satisfaction,

depression and anxiety. This was done using Schulz and colleagues' (2010) suffering measures, in conjunction with the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) and the Interpersonal Reactivity Index (Davis, 1980).

Primarily, authors sought to examine the relationships between perceived suffering, cognitive and affective empathy, satisfaction, and depression and anxiety within caregivers. The authors hypothesised that perceived suffering of IWDs would be positively correlated with caregiver depression, as previously found by Schulz *et al.* (2008). The authors were also interested in examining what relationships exist between caregiver anxiety and caregiver depression, and between caregiver anxiety and the perceived suffering of IWDs. It was also hypothesised, based on existing research with populations of paid caregivers and health professionals, that there may be some associations between affective and cognitive empathy and caregiver depression and anxiety (e.g. Robins *et al.*, 2009). With regards to caregiver satisfaction, it was hypothesised that satisfaction would be negatively correlated with caregiver depression, which is in keeping with existing models of compassion fatigue and research into the positive aspects of caregiving (e.g. López *et al.*, 2005; Piiparinen & Whitlatch, 2011). It was hypothesised that there may also be a relationship between caregiver satisfaction and caregiver anxiety.

A second objective was to use exploratory analyses to understand what associations exist between IWDs' self-reported levels of suffering and their self-reported depression and anxiety levels. These analyses are new in the literature and do not appear to have been examined previously.

Finally, the levels of suffering self-reported by IWDs and perceived by caregivers were examined in order to explore inter-person and intra-person correlations. The authors sought to identify mental health variables that were associated with greater levels of discrepancy between the self-reported and perceived levels of suffering of the IWDs. It was hypothesised that caregiver depression and IWDs' depression may be positively

correlated with increased levels of discrepancy between suffering ratings, as found in previous research (Schulz *et al.*, 2013; Logsdon *et al.*, 2002). The authors sought to examine whether any similar relationships existed between levels of discrepancy, and caregiver anxiety or IWDs' anxiety.

To the authors' knowledge this is the first study to empirically investigate cognitive and affective empathy in caregivers. It is also the first to explore the relationship between levels of suffering and caregiver anxiety. The analyses within this study are therefore unique in this literature and begin to explore potential associations that may be critical to developing models for understanding and addressing caregivers' psychological outcomes. The potential theoretical and clinical implications of these exploratory results, as well as suggested future directions, will therefore be discussed.

Methods

Ethical Approval

Ethical approval for the study was obtained through the relevant committees at the University of Edinburgh and at the East of Scotland Research Ethics Service (EoSRES) in March 2013 (REC Reference Number: 13/ES/0019). The research was also conducted according to the British Psychological Society's (BPS) Code of Conduct for research with human participants (BPS, 2006). Due regard was given to procedures such as informed consent, data security, confidentiality and right to withdraw.

Participants

Participants recruited were dyads of caregivers and their partners with diagnoses of probable mild to moderate Alzheimer's Disease, Vascular Dementia or Mixed Dementia. Participants were included if they were 18 years or older, spoke English fluently and were community-dwelling. Couples were eligible if they had lived together for a minimum of five years and if partners identified themselves as the primary caregiver of the IWD. Participants were initially recruited within Tayside, Grampian, Fife and Greater Glasgow and Clyde Health Boards through postal information packages

sent to potentially eligible dyads enrolled on the Scottish Dementia Clinical Research Network (SDCRN) research register. Further recruitment was conducted in NHS Tayside through the Older People Community Mental Health Teams (CMHT-OPs) and the Early Stage Dementia Support Services. Clinicians in these services approached dyads who met inclusion criteria and offered them written information inviting them to participate in the study.

Procedure

The study employed a cross-sectional survey methodology where dyads of caregivers and IWDs completed questionnaires during face-to-face interviews. Through contact by means of the recruitment pathways described above, potential participants were provided with written information detailing the nature and purpose of the study. Potential participants were instructed in the Participant Information Forms to return an enclosed Consent Form or to telephone the lead researcher (RS) if they wished to take part or learn more about the research. Where potential participant dyads expressed an interest in participating, an initial meeting was arranged with the lead researcher (RS) at a mutually convenient time and place.

All interviews were conducted by the lead researcher (RS) and lasted an average of 120 minutes for each dyad. At the commencement of the interview, the researcher outlined the purpose of the study and engaged participants individually in informed consent procedures. In instances where either individual was unable to provide informed consent, the interview was terminated and any data collected from the dyad was excluded from data analysis. To ensure that participants' responses to measure items were not influenced by partners, interviews were conducted with IWDs and caregivers on a one to one basis.

Measures

All outcomes measures were completed during face-to-face interviews. During administration of the measures, response cards indicating the response choices in large

font sizes on high-contrast backgrounds were given to participants at appropriate times. These were used to assist participants with their selection of responses to the test items.

Caregivers were asked to provide demographic information for both themselves and their partners. In addition, they were asked to complete measures regarding their level of anxiety and depression, cognitive and affective empathy, and caregiver satisfaction. Caregivers were also asked to complete a measure on their perception of the levels of suffering in their partner with dementia (i.e. the perceived level of suffering). Individuals with dementia were asked to complete measures regarding their own levels of anxiety, depression and suffering (i.e. the self-reported level of suffering). A brief cognitive assessment was also completed with IWDs in instances where no recent score (i.e. from within the past eight months) was available.

Demographic and Background Information – The following demographic characteristics were collected for caregivers and IWDs: age, sex, level of education, marital status and occupational status. Caregivers were asked about the type of dementia diagnosis given and time since diagnosis. Information regarding the physical and mental health histories of both individuals was also collected. The dyads' residential postcode was used to estimate socioeconomic status using data from the Scottish Index of Multiple Deprivation (SIMD; National Statistics Publication for Scotland, 2012). In addition, both caregivers and IWDs were asked to rate their overall quality of life on a scale from 1 to 10, where 10 indicated the maximum possible level of quality of life.

Suffering Measures – To measure the self-reported levels of suffering of the IWDs, as well as perceived levels of IWDs' suffering as rated by the caregiver, the Suffering scales (Schulz *et al.*, 2010; 2013) were administered to IWDs and caregivers. Standard administration and scoring procedures as outlined by Schulz and colleagues (2010; 2013) were used. This instrument includes three subscales which measure psychological, physical and existential suffering of the IWD over the past 7 days. Physical suffering is measured with 9 items assessing symptoms such as pain, nausea, shortness of breath and

dry mouth, which give an index score of 0 to 9. Psychological suffering is measured with 15 items assessing the frequency at which different emotions (e.g., confident, depressed, abandoned, cheerful, etc.) are experienced, and gives an index score of 0 to 45. Existential suffering is measured with 9 statements (e.g. “I feel peaceful”, “My life has been a failure”, “Life is not worth living anymore”) where respondents are asked to indicate how true each statement is for the IWD. An index score is yielded ranging from 0 to 36. For all subscales, higher scores indicate greater levels of suffering. These scales have been shown to have high levels of internal consistency, test-retest reliability, and convergent and discriminant validity (Schulz *et al.*, 2010).

Hospital Anxiety and Depression Scale – The HADS (Zigmond & Snaith, 1983) was administered to caregivers and IWDs to measure self-reported levels of anxiety and depression. This measure contains two seven-item subscales, which assess levels of anxiety and depression within the past week. Each item is scored on a four-point scale and summed to generate subscale scores ranging from 0 to 21. The subscales provide cut-offs that allow for discrimination between Non-clinical (scores of 0–7), Mild (8–10), Moderate (11–14) and Severe (15–21) levels of anxiety and depression (Crawford *et al.*, 2001). Good reliability and validity against clinical diagnosis in the general population has been demonstrated for this measure (Bjelland *et al.*, 2002). It is also recommended for use with older people in the UK as a result of its practicality, feasibility, UK relevance and psychometric properties (Sperlinger *et al.*, 2004).

The Interpersonal Reactivity Index – The IRI (Davis, 1980) was used to measure the levels of cognitive and affective empathy in caregivers. This instrument contains four seven-item subscales: (1) empathic concern (EC); (2) personal distress (PD); (3) perspective taking (PT); and (4) fantasy (FS). These subscales measure an individual’s emotional concern for others (EC), negative feelings in response to the distress of others (PD), cognitive understanding of the perspective of others (PT), and ability to emotionally identify with fictional characters (FS). Each of the 28 items is rated using a five-point Likert scale, ranging from 0 (‘does not describe me well’) to 4 (‘describes me

very well'). The EC and PD scales are used to measure the respondent's level of affective empathy and the PT and FS scales measure the level of cognitive empathy. Negative items are reverse scored. Item scores are summed to calculate four index scores (range of 0–28), where higher scores indicate higher levels of empathy. Davis (1980) reported that the scales have satisfactory internal and test-retest reliabilities in the general population. Significant sex differences have been reported within the measure, with females scoring higher than males on each of the four subscales.

Caregiver Satisfaction Scale – The perceived positive aspects of caregiving were measured using the CSS (Lawton *et al.*, 1989b) with caregivers. This scale contains six items. Five items describe positive outcomes from caregiving (e.g. enjoying being with the individual, feeling closer to the individual, etc.) and a sixth item asks the caregiver to rate their global satisfaction in caring for the IWD. This instrument has been shown to have good test-retest reliability and internal consistency for caregivers who live at home with their partners or relatives (Lawton *et al.*, 1989b; Brody *et al.*, 1992). Full-scale scores range from 6 to 30. Higher scores indicate higher levels of satisfaction.

Addenbrooke's Cognitive Examination – Third Edition – The ACE-III (Hsieh *et al.*, 2013) was used to assess the current overall cognitive functioning of the IWDs. This is a newly developed version of a brief, sensitive and specific cognitive screening instrument that incorporates five domains: attention, verbal memory, language and visuospatial functioning. These domains have been found to be significantly correlated with existing standardised cognitive screening tools and to have similar levels of sensitivity and specificity compared to the predecessor, the ACE-R (Hsieh *et al.*, 2013). Where an ACE-III had been completed in the last eight months and the score was available in the SDCRN register or clinical notes, the IWD did not complete the ACE-III in interview.

Sample Size and Power Calculations

Prospective power analyses were conducted to estimate the sample size necessary to ensure the methodological integrity of the study.

Previous research using one of the study's primary independent variable (caregiver depression) has generally reported medium correlations (0.28 – 0.38) with perceived levels of suffering (Schulz *et al.*, 2010). In addition, previous research has indicated a trend towards small correlations between caregiver satisfaction and depression (-0.217) and between caregiver satisfaction and anxiety (-0.173) (López *et al.*, 2005). Given the exploratory nature of this study, associations between many of the included variables have not been previously investigated despite potential theoretical associations. Therefore, on the basis of little previous research and existing theoretical models, authors calculated the required sample size using a predicted medium correlation size of 0.3 between variables.

Computer software for power calculations (G*Power, version 3.1) was used to calculate an a priori sample size. This calculation suggested that in order to have 0.8 power to detect medium sized correlations at an alpha level of 0.05, when carrying out bivariate correlational analysis, a sample size of 84 couples would be required.

Data Analysis

Raw data were entered into and analysed using SPSS Version 20. The normality of the data distributions for the HADS, IRI, CSS, and Suffering measures were examined using histograms and *z* scores for skewness and kurtosis. Data integrity was confirmed. Parametric tests were used despite the relatively low sample size, as the data met the assumptions of parametric data at acceptable levels.

Descriptive statistics were initially used to inspect the characteristics of the IWDs group and the caregiver group, including demographics, relationship characteristics, illness characteristics and indicators of quality of life and mental health. In addition, the internal consistency of the Suffering measures was examined using Cronbach's alphas.

Bivariate correlational analyses followed. First, these were used to test exploratory hypotheses regarding the relationships between the variables of perceived suffering,

cognitive and affective empathy, caregiver satisfaction, and depression and anxiety in the caregivers.

Second, correlations were used to explore the relationships between IWDs' self-reported levels of suffering, anxiety and depression.

Third, correlational analyses were used to explore the concordance and discrepancies among the perceived and self-reported suffering measures completed by IWDs and caregivers.

Finally, correlations were calculated to test exploratory hypotheses regarding possible relationships between the discrepancies in suffering measures, and the anxiety and depression scores of caregivers and IWDs.

Given the exploratory nature of the research and the multiple comparisons being tested, Bonferroni corrections were implemented across each set of analyses to control for family-wise errors as recommended (Field, 2013). Calculation of Bonferroni correction for multiple comparisons yielded an adjusted significance level of $p < 0.0011$ (two-tailed tests). Comparisons meeting Bonferroni-corrected alpha levels are indicated in Tables 3–6. For brevity, results not reaching the corrected level of significant are not presented in the text, with the exception of some results that show a trend towards significance.

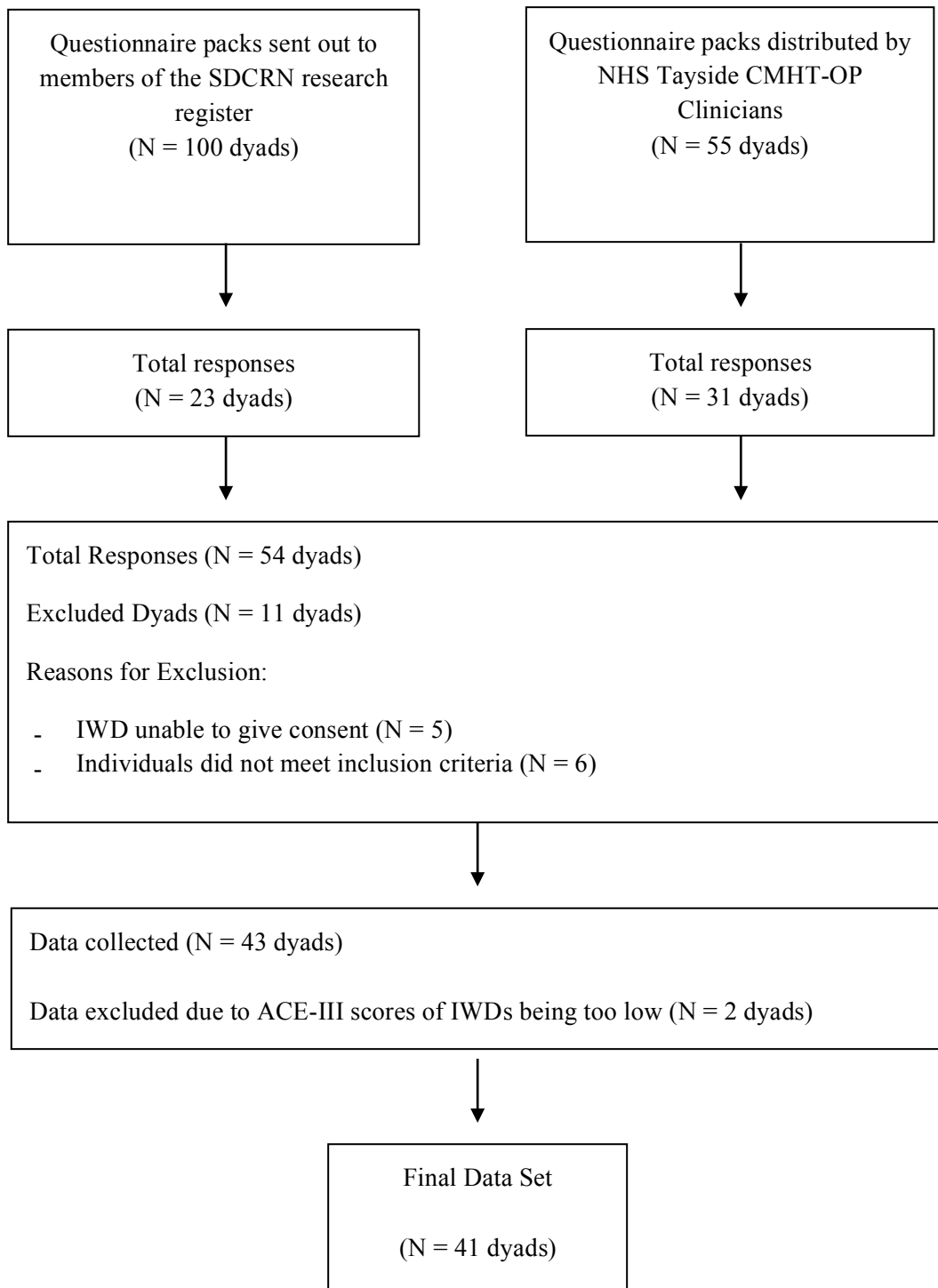
Results

Recruitment for the Study

Figure 1 illustrates the recruitment pathway of participants. Between August 2013 and September 2014, a total of 155 dyads were approached. Of these, 54 dyads initially responded and were screened for eligibility. This indicates a response rate of 34.8%, which is consistent with the average rate for questionnaire based psychological research (Cook *et al.*, 2000). Data was not collected from 11 dyads. The reasons for exclusion were: the person with dementia being unable to consent (N = 5) and the dyad not meeting the study inclusion criteria (N = 6).

Data collected from two dyads was excluded from analysis. This decision was made due to IWDs' low scores on the ACE-III. It was decided that given these scores, the individual's ability to complete the other measures may have been compromised. The final sample therefore consisted of a total of 41 dyads.

FIGURE 1: Study Recruitment Pathways and Numbers



Data Integrity and Distribution

There were no missing data for interviewed dyads. Data were visually screened for the identification of outliers. A preliminary analysis was carried out to assess the normality of the distribution of data to ensure that the assumptions for parametric testing were met. Histograms were visually inspected and tests of skewness and kurtosis were performed for the following: HADS, IRI, CSS and the suffering measure. Scores were converted into z-scores following recommendations by Field (2013), where a z score of more than ± 1.96 for large samples or ± 2.58 for smaller samples signifies a non-normally distributed sample. Given the small sample size, the authors adopted the ± 2.58 range to assess normality in the data set. Examination of the data from HADS, IRI, CSS and suffering measures with this approach indicated that the assumption of normality was not violated. Homogeneity of variance, using the Levene's test for equality of variances was not used due to the small sample size and equal group sizes (Field, 2013).

Demographics, Relationship Characteristics and Illness Characteristics

Demographic characteristics of the IWDs and caregivers are presented in Table 1. Ages of the IWDs ranged from 59 to 90 (mean = 77.5, SD = 7.1), and were similar to those of the caregivers (mean = 75.8, SD = 7.1; range: 60–88). There were a greater proportion of female caregivers in the sample (58.5%), however the ratio of female to male caregivers was not as disproportionate as that found in previous studies (e.g. 80% female in Schulz *et al.*, 2008; 2013). On average, IWDs had marginally higher levels of educational attainment than their caregivers, however the majority of participants ($n = 54$, 65.8%) did not report having any qualifications beyond secondary school. The sample was comprised entirely of individuals who described themselves as White British.

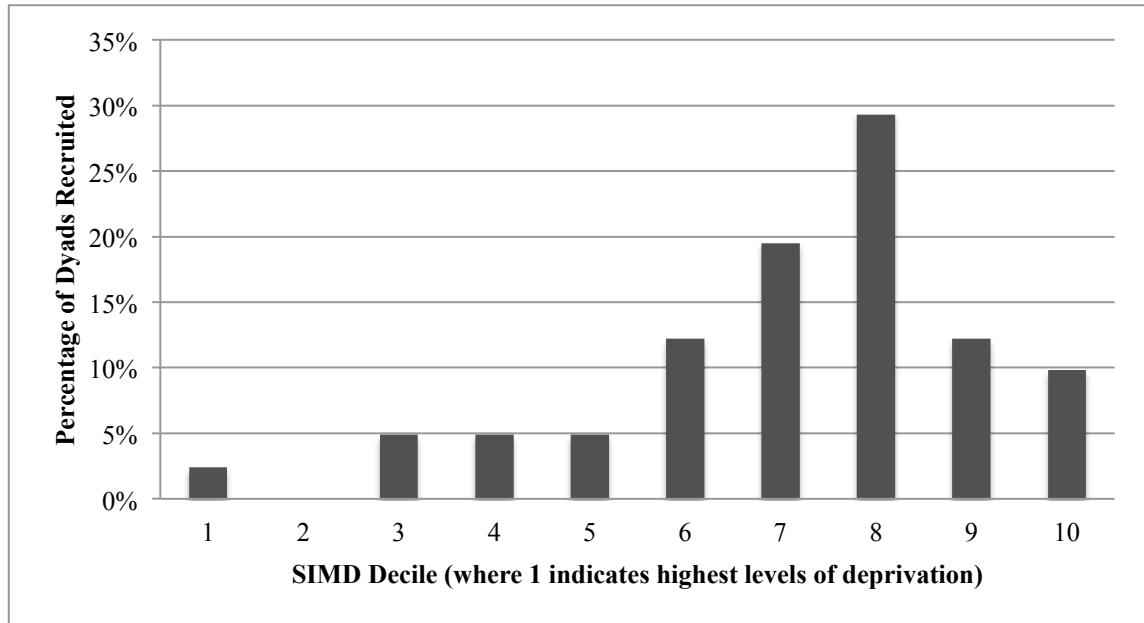
As described in the inclusion criteria, all caregivers had lived with the IWD for more than 5 years. The majority of couples (82.9%) had lived together for more than 30 years. Only one dyad of participants interviewed was not married.

TABLE 1 Characteristics of Individuals with Dementia (IWDs) and their Caregivers

| | IWDs (N = 41) | Caregivers (N = 41) |
|--|--------------------------|--------------------------------|
| Age | | |
| Mean (SD) | 77.5 (7.1) | 75.8 (7.1) |
| Range | 59.5 – 90.4 | 60.8 – 88.1 |
| Sex, N (%) | | |
| Female | 17 (41.5%) | 24 (58.5%) |
| Male | 24 (58.5%) | 17 (41.5%) |
| Years in Education, mean (SD) | 12.0 (2.4) | 11.5 (2.5) |
| Socio-economic status determined by index of deprivation (SIMD), mean (SD) | 7.1 (2.0) | |
| Relationship Status, N (%) | | |
| Married | | 40 (97.6%) |
| Unmarried | | 1 (2.4%) |
| Length of Relationship (years) | | |
| Mean (SD) | | 46.0 (15.0) |
| Range | | 6–66 |
| Type of Dementia, N (%) | | |
| Alzheimer's Disease | 26 (63.4%) | |
| Vascular Dementia | 7 (17.1%) | |
| Mixed Dementia | 8 (19.5%) | |
| Years since diagnosis | | |
| Mean (SD) | 3.2 (2.9) | |
| Range | 2 months – 16 years | |
| Cognitive Functioning (ACE-III), mean (SD) | 63.4 (14.7) | |
| IWDs mental health status and quality of life | | |
| Depression (HADS-D), mean (SD) | 4.6 (3.2) | |
| Anxiety (HADS-A), mean (SD) | 4.7 (3.3) | |
| Self-rated QOL, mean (SD) | 7.0 (2.0) | |
| Prescribed Medication for Dementia, N (%) | 30 (73.2%) | |
| Self-reported mental health history, N (%) | 12 (29.3%) | |
| Caregiver mental health status and quality of life | | |
| Depression (HADS-D), mean (SD) | | 4.7 (3.2) |
| Anxiety (HADS-A), mean (SD) | | 7.4 (3.9) |
| Self-rated QOL, mean (SD) | | 6.4 (1.8) |
| Self-reported mental health history, N (%) | | 17 (41.5%) |
| Currently prescribed psychiatric medication, N (%) | | 8 (19.5%) |

Notes: QOL: Quality of Life rating; ACE-III: Addenbrooke's Cognitive Examination, Third edition; HADS: Hospital Anxiety and Depression Scale.

FIGURE 2: Distribution of Recruited Dyads Across SIMD Deciles



The Scottish Index of Multiple Deprivation (SIMD) decile point scale was used to estimate the socioeconomic status (SES) of participants. This scale defines SES according to postcodes using a 10-point scale, where 1 indicates highest levels of deprivation in Scottish communities (Scottish Government, 2012). The majority of participants (70.8%) lived in the four least deprived SIMD areas (see Figure 2).

The majority of participants (63.4%) had a probable diagnosis of Alzheimer's disease (see Table 1). Vascular Dementia (17.1%) and Mixed Dementia (19.5%) diagnoses were, as would be expected, less common in the recruited sample. On average, IWDs had received their diagnoses approximately 3.2 years prior to interview, however the length of time since diagnosis did vary (2 months – 16 years).

Individuals with dementia had an average score of 63 on the ACE-III. Scores fell within the probable mild to moderate range of cognitive functioning, although this is difficult to assess because of the potentially diverse pre-morbid functioning of individuals. ACE-III scores of less than 82–88 generally indicate potential dementia (Hsieh *et al.*, 2013). Only one IWD had an available ACE-III score recorded within the previous 8 months.

Mental Health Indicators

Quality of life and mental health indicators for IWDs and caregivers are also presented in Table 1. Caregivers' average level of depression, as measured by the HADS subscale, fell within the Normal range (mean = 4.7; SD = 3.2). Caregivers presented with an average score of 7.4 (SD = 3.9) on the HADS anxiety subscale. This indicates a level of anxiety just below the Mild range.

It was found that for depression, the majority of caregivers (82.9%) fell within the Normal range on the HADS Depression subscale. Only 7.3% of caregivers scored within the Mild range, 9.7% in the Moderate range and none in the Severe range. As a result, only 17.1% of caregivers presented with clinical levels of depression.

A smaller percentage of caregivers (46.3%) fell within the Normal range on the anxiety subscale. A total of 39.0% of caregivers scored within the Mild anxiety range, 9.8% within the Moderate range and 4.9% within the Severe range. This suggests that 53.7% of the recruited caregivers presented with clinical levels of anxiety.

Among caregivers, 100% of those that presented with clinical levels of depression on the HADS (N = 7), also presented with clinical levels of anxiety. Of those caregivers that presented with clinical levels of anxiety (N = 22), 31.8% presented with clinical levels of depression.

The average level of depression among IWDs, as measured by the HADS, fell within the Normal range (mean = 4.6; SD = 3.2). The average level of IWDs' anxiety for was also within the Normal range (mean = 4.7; SD = 3.3). The majority of IWDs (82.9%) fell within the Normal range on the HADS depression subscale, 12.2% within the Mild range and 4.9% within the Moderate range. On the HADS anxiety subscale, 80.5% fell within the Normal range, 12.2% within the Mild range and 7.3% within the Moderate range. No IWDs fell within the Severe range of the anxiety or depression subscales.

Internal Consistency of the Suffering Scales

TABLE 2 Internal Consistency of the Suffering Scales in the Present Study and in Schulz *et al.*, 2013

| Suffering Measure | Present Study | | Schulz <i>et al.</i> , 2013 | |
|--------------------------|----------------------------------|------------|----------------------------------|------------|
| | Individuals with Dementia (IWDs) | Caregivers | Individuals with Dementia (IWDs) | Caregivers |
| N | 41 | 41 | 79 | 105 |
| Physical suffering index | | | | |
| Cronbach's alpha | .75 | .58 | .53 | .49 |
| Range | 0–7 | 0–7 | 0–7 | 0–6 |
| Mean (SD) | 1.9 (1.8) | 2.9 (1.5) | 1.0 (1.3) | 2.0 (1.4) |
| Psychological Suffering | | | | |
| Cronbach's alpha | .77 | .80 | .86 | .87 |
| Range | 0–22 | 2–29 | 0–32 | 1–38 |
| Mean (SD) | 8.1 (5.2) | 12.1 (5.8) | 7.5 (6.7) | 11.7 (7.0) |
| Existential Suffering | | | | |
| Cronbach's alpha | .76 | .82 | .85 | .86 |
| Range | 0–26 | 1–26 | 0–28 | 0–33 |
| Mean (SD) | 8.6 (5.7) | 12.3 (6.6) | 6.2 (5.9) | 11.6 (6.6) |

Cronbach alphas were calculated for the suffering measure subscales and compared to Schulz and colleagues' (2013) findings (see Table 2). Results show the internal consistencies are relatively comparable to previous findings. The Cronbach alphas are also almost all above .60, which is the recommended level for a self-report measure to be reliable (Bernstein & Nunnally, 1994). As noted by Schulz and colleagues (2013), it is expected that the physical domain of suffering may have a lower level of internal consistency as it measures an index of physical symptoms which are not necessarily inter-correlated. Caregivers and IWDs in the present sample reported a narrower range of psychological and existential suffering than Schulz and colleagues' sample (2013).

Relationships between Levels of Empathy, Satisfaction and Perceptions of the Suffering of IWDs, and Caregiver Depression and Anxiety

To examine relationships between caregiver's levels of empathy, satisfaction and perceived suffering, and caregiver depression and anxiety, a correlation matrix was used

(see Table 3). It should be noted that a significant large positive correlation between the Depression and Anxiety subscales of the HADS ($r = .703, p = .0000$) was found.

Perceived Suffering

There were no significant correlations found between the perceived suffering variables and caregiver depression or anxiety using the stringent Bonferroni corrected alpha level. However, positive correlations between perceived psychological suffering and caregiver depression ($r = .392, p = .0112$), and between perceived existential suffering and caregiver depression ($r = .368, p = .0180$), showed a trend towards significance. In addition, a significant positive correlation was found between perceived existential suffering and perceived psychological suffering ($r = .513, p = 0.0006$).

Empathy

The raw Pearson correlations between the four IRI subscales (Fantasy, Empathic Concern, Perspective Taking and Personal Distress), and levels of caregiver anxiety and depression were all statistically non-significant. Therefore, there is no evidence to suggest that these variables demonstrated the hypothesised theoretically predicted associations. There was no evidence that higher levels of the affective empathy (i.e. EC and PD) were associated with high levels of caregiver depression and anxiety. There was also no evidence to suggest that higher levels of cognitive empathy (i.e. FS and PT) were associated with lower levels of depression or anxiety. A statistically significant positive correlation was found between the Perspective Taking and Empathic Concern subscales ($r = .522, p = .0005$).

Satisfaction

No statistically significant correlations were found between caregiver satisfaction and the other variables. However, there was a trend towards significance in the negative correlation between caregiver satisfaction and caregiver anxiety ($r = -.451, p = .0031$).

TABLE 3 Raw Pearson Bivariate Correlations between Caregiver Anxiety and Depression and Measures of Empathy, Satisfaction and Perceived Suffering of IWDs

| Variable | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|--------------------------------------|-------|-------|-------|-------|-------|-------|-------|-------|------|
| 1. Caregiver Depression (HADS-D) | - | - | - | - | - | - | - | - | - |
| 2. Caregiver Anxiety (HADS-A) | .703* | - | - | - | - | - | - | - | - |
| 3. Perceived Physical Suffering | .185 | .001 | - | - | - | - | - | - | - |
| 4. Perceived Psychological Suffering | .392 | .082 | .289 | - | - | - | - | - | - |
| 5. Perceived Existential Suffering | .368 | .257 | .186 | .513* | - | - | - | - | - |
| 6. IRI – Fantasy (FS) | .038 | .046 | -.308 | -.034 | -.314 | - | - | - | - |
| 7. IRI – Empathic Concern (EC) | .068 | .103 | -.039 | -.102 | -.128 | .117 | - | - | - |
| 8. IRI – Perspective Taking (PT) | .198 | .053 | -.071 | .385 | .112 | .140 | .522* | - | - |
| 9. IRI – Personal Distress (PD) | .027 | .018 | -.152 | -.210 | -.126 | -.103 | -.179 | -.028 | - |
| 10. CSS | -.238 | -.451 | .110 | .031 | -.422 | .273 | .082 | .251 | .141 |

Notes:

CSS: Caregiver Satisfaction Scale; HADS: Hospital Anxiety and Depression Scale; IRI: Interpersonal Reactivity Index.

* $p < 0.001$ (Bonferroni Corrected alpha level)

Relationships between IWDs' Self-Reported Levels of Suffering and IWDs' Depression and Anxiety

A bivariate correlation matrix was used to examine relationships between IWDs' self-reported levels of suffering and their levels of depression and anxiety (see Table 4).

A significant positive correlation was found between IWDs' level of depression and their self-reported psychological suffering ($r = .615$, $p = .0000$). The IWDs' level of depression was also found to be positively correlated with self-reported existential suffering ($r = .516$, $p = .0005$). In addition, a significant positive correlation was found between self-reported psychological suffering and IWDs' level of anxiety ($r = .520$, $p = .0005$). The correlation between self-reported physical suffering and IWDs' levels of depression showed a trend towards significance ($r = .325$, $p = .0381$).

TABLE 4 Raw Pearson Bivariate Correlations between Anxiety and Depression in Individuals with Dementia (IWDs) and Self-Reported Suffering of IWDs

| Variable | 1 | 2 | 3 | 4 | 5 |
|--|-------|-------|-------|-------|---|
| 1. IWD Depression (HADS-D) | - | - | - | - | - |
| 2. IWD Anxiety (HADS-A) | .300 | - | - | - | - |
| 3. Self-reported Physical Suffering | .325 | .149 | - | - | - |
| 4. Self-reported Psychological Suffering | .615* | .520* | .556* | - | - |
| 5. Self-reported Existential Suffering | .516* | .280 | .107 | .538* | - |

Notes:

* $p < 0.001$ (Bonferroni Corrected alpha level)

HADS: Hospital Anxiety and Depression Scale.

Correlations and Discrepancy Among Measures of Suffering

Table 5 presents the raw Pearson correlations between the caregiver and IWD ratings of the dimensions of suffering. Correlations between caregivers' and IWDs' ratings were all within the medium to large range, however only the correlation between self-reported and perceived psychological suffering was found to be significant ($r = .501, p = .000$). Although the correlations for physical and existential suffering were not found to be significant, according to Steiger (1980), the difference between all three correlations was not found to be significant. This suggests that these correlations show a trend towards significance. Paired t-tests demonstrated that caregivers reported significantly higher levels of perceived suffering, across all three subscales, than those self-reported by IWDs. Correlation comparisons (as recommended by Cohen *et al.*, 2013) showed that the current findings were not significantly different from Schulz *et al.* (2013) findings. It should be noted that Schulz *et al.* used a different significance level.

TABLE 5 Suffering Measures: Means, Standard Deviations and Measures of Concordance between Individuals with Dementia (IWDs) and Caregivers

| | Present Study | | | | Schulz <i>et al.</i> , 2012 | |
|--------------------|------------------------|------------------|---|--------------------------------------|---|--------------------------------------|
| | Caregivers (n = 41) | IWDs (n = 41) | Paired Difference ^a Caregiver – IWD | Correlation ^b <i>r</i> | Paired Difference ^c Caregiver – IWD | Correlation ^d <i>r</i> |
| Suffering measures | | | | | | |
| Physical (index) | 2.9 (1.5) | 1.9 (1.8) | 1.0 (1.8)** | .386 | 1.0 (1.7)* | .288* |
| Psychological | 12.1 (5.8) | 8.1 (5.2) | 4.0 (5.6)** | .501** | 4.0 (7.5)* | .345* |
| Existential | 12.3 (6.6) | 8.6 (5.7) | 3.7 (6.7)** | .406 | 4.6 (7.4)* | .279 |

Notes:

* $p < 0.01$ (Level reported by Schulz *et al.*, 2012)

** $p < 0.001$ (Bonferroni Corrected alpha level)

^a Paired *t* test ($df = 40$) comparing difference in raw scale scores between caregiver and IWD ratings.

^b Raw Pearson correlation ($df = 39$) between caregiver and IWD ratings for each scale.

^c Paired *t* test ($df = 78$) comparing difference in raw scale scores between caregiver and IWD ratings.

^d Raw Pearson correlation ($df = 77$) between caregiver and IWD ratings for each scale.

Correlations between Discrepancies in Suffering Ratings and Mental Health Indicators of Caregivers and Individuals with Dementia (IWDs)

Bivariate correlations were used to investigate the relationships between the discrepancies in the suffering ratings, and depression and anxiety scores in caregivers and IWDs (see Table 6). No significant correlations were found in these analyses. However, a non-significant moderate positive correlation was found between caregiver depression and the discrepancy in psychological suffering ($r = .351$, $p = .025$).

TABLE 6 Raw Pearson Bivariate Correlations between Discrepancies in Suffering Ratings and the Depression and Anxiety of Caregivers and IWDs

| Variable | Discrepancy ^a in Physical Suffering | Discrepancy in Psychological Suffering | Discrepancy in Existential Suffering |
|-------------------------------|--|--|--------------------------------------|
| Caregiver Mental Health | | | |
| Caregiver Depression (HADS-D) | .020 | .351 | .256 |
| Caregiver Anxiety (HADS-A) | -.041 | .181 | .218 |
| IWD Mental Health | | | |
| IWD Depression (HADS-D) | -.101 | -.197 | -.235 |
| IWD Anxiety (HADS-A) | -.078 | -.202 | -.157 |

Notes:

* $p < 0.001$ (Bonferroni Corrected alpha level)

HADS: Hospital Anxiety and Depression Scale.

^a Discrepancy ratings were calculated as follows: Caregiver score – IWD score

Discussion

This study sought to expand on previous literature by conducting preliminary exploratory analyses into the relationships between suffering, empathy, satisfaction, and caregivers' and IWDs' depression and anxiety, using a dyadic approach.

Mental Health Outcomes

The results of the present study highlight the striking levels of anxiety within the caregiver population. Although only 17.1% of caregivers presented with clinical levels of depression, 53.7% reported clinical levels of anxiety. This indicates lower rates of depression than the 22.3% estimated prevalence rate (Cuijpers, 2005). However, the rate of anxiety in this sample is significantly higher than the reported 25% prevalence in the

literature (Cooper *et al.*, 2007a).

The high prevalence rate of anxiety is a striking finding. The caregivers were recruited as a result of their partners' contact with services and were not from a clinical sample. This research therefore further highlights the importance of researchers investigating and measuring caregiver anxiety, as well as depression, in order to accurately understand the presence of these common psychological outcomes in caregivers. It also highlights the need for clinicians to regularly assess and monitor anxiety levels in caregivers. Clinicians and services need to be offering evidence-based psychological interventions or advice to these caregivers, as appropriate.

Results also found that caregiver depression and anxiety were significantly positively correlated (.703), suggesting that a high level of co-morbidity may be present in this population. Previous standardisation of the HADS has shown that correlations between the two subscales can vary between .40 and .74 (mean .56) in the literature (Bjelland *et al.*, 2002). Therefore, this result may not be specific to caregivers. However, this result is in line with previous research which has shown a positive correlation of .87 between anxiety and depression scores in caregivers (García-Alberca *et al.*, 2011). Compared to Beekman and colleagues (2000), it was found that 100% in the current sample of those with clinical levels of depression also met clinical levels of anxiety, and 31.8% with clinical levels of anxiety also met criteria for depression. Therefore, the co-morbidity in this caregiver sample is higher than that found in Beekman's general elderly population.

Factors Associated with Caregiver Depression and Anxiety

Correlational analyses conducted demonstrated no significant relationships between caregiver depression and anxiety, and the variables of perceived suffering, empathy and caregiver satisfaction. This was inconsistent with previous findings where perceived psychological and existential suffering were positively associated with caregiver depression (Schulz *et al.*, 2008). However, trends towards significant were found for the correlations between caregiver depression, and perceived psychological and existential suffering. Further research may therefore be required to test these associations further.

There was no evidence to suggest that caregiver anxiety varied as a function of perceived levels of suffering. Previous research has suggested that there are strong relationships between caregivers' coping strategies and their level of anxiety (e.g. Cooper *et al.*, 2007a). One possible explanation for this finding might be that perceived suffering does not directly correlate with anxiety, but may instead be mediated by caregivers' coping strategies. Further research using mediational analysis or a longitudinal design would be necessary to explore this hypothesis further. The present results also do not provide any evidence that the perception of suffering is associated with the co-morbidity of anxiety and depression in caregivers.

There was no evidence to suggest that the four domains of cognitive and affective empathy demonstrated significant associations with caregiver depression and anxiety. Caregiving satisfaction was also not found to be significantly associated with caregiver anxiety or depression. However, there was a trend towards a significant negative association between caregiver satisfaction and caregiver anxiety. This is an interesting finding as previous research has demonstrated that positive reappraisal coping, which describes caregivers' efforts to create positive meaning by focusing on personal growth, is not associated with caregiver anxiety (Folkman *et al.*, 1986; Neundorfer, 1991; Vedhara *et al.*, 2001). Further research would be required to explore these relationships within a larger sample.

Perceived and Self-Reported Levels of Suffering

As hypothesised, significant positive correlations were found between some dimensions of self-reported suffering and IWDs' self-reported levels of anxiety and depression. This suggests that the suffering scales and the HADS may measure similar constructs and therefore supports the face validity of the suffering scale.

In addition, caregivers were found to perceive significantly higher levels of suffering than IWDs self-reported. This provides further evidence to the literature regarding the discrepancy between caregivers and IWDs' reports of well-being and mental health indicators (e.g. Novella *et al.*, 2006; Sands *et al.*, 2004; Schulz *et al.*, 2013).

Unlike previous results (Schulz *et al.*, 2013), caregiver depression was not found to be positively associated with the discrepancy in psychological or existential suffering scores. In addition, no relationships were found between caregiver anxiety and the discrepancy scores. One reason for this finding may be the lower levels of depression in the current sample, or the smaller range in suffering scores when compared to Schulz and colleagues' (2013) findings. It may also be that the lack of direct relationships is as a result of other mediating variables. For example, the coping style of the caregiver has previously been implicated as a predictor of anxiety (Cooper *et al.*, 2007a) and may therefore be a relevant variable in understanding these relationships. However, similar to Schulz and colleagues' (2013) results, the studied variables do not fully account for the discrepancy between caregiver and patient ratings of patient suffering. Therefore, given the relatively large differences in suffering ratings, an important question remains regarding what else might account for these discrepancies.

Limitations

One limitation of this study is the small sample size. Recruitment of dyads, where both individuals were willing and able to consent to participation, was a significant challenge. Although several recruitment methods were adopted and a wide geographical area covered, the final sample size is still smaller than previous studies investigating caregiver suffering (e.g. Schulz *et al.*, 2010, 2013). The sample was also smaller than the sample size ($n = 84$ dyads) calculated as necessary to reliably detect medium sized correlations. Given the large number of statistical tests completed and the sample size, results must therefore be interpreted cautiously due to the potential for Type I and Type II errors. Nonetheless, Bonferroni Correction procedures were implemented to employ a more stringent level of significance. This will have reduced the likelihood of family-wise errors and increased the likelihood of generalisable results.

A cross-sectional methodology was used for this exploratory research, which also does limit understanding regarding the relationships between explored variables. A number of theoretical explanations for the examined relationships can be hypothesised, however without longitudinal methodology to explore the direction and causality of relationships,

it remains difficult to fully interpret the associations between these variables.

Despite these limitations, the decision to employ the chosen methodology does mean that the present research adds to a relatively small body of literature that has examined caregiver outcomes from a dyadic perspective (Braun *et al.*, 2009; 2010). Given the hypothesised interpersonal nature of suffering and empathy, it remains crucial that research investigating these variables is conducted with dyads of caregivers and care recipients, rather than focusing only on the caregivers or the IWDs. Without this dyadic approach, we run the risk of overlooking key interpersonal variables in the development of caregiver outcomes.

Implications and Future Directions

The results of this study clearly identify several continuing areas of need in caregiver research and care.

First, the results highlight the high levels of caregiver anxiety. Future research should aim to increase identification and understanding of anxiety in caregivers. Greater knowledge regarding the factors that are associated with the development, maintenance and impact of anxiety remains necessary. Research that examines anxiety within the context of co-morbidity with depression is also recommended. From a clinical perspective, it remains imperative that services identify anxiety within caregivers and offer appropriate and effective psychological intervention to improve caregiver outcomes.

Second, further understanding of the variability in the levels of perceived suffering requires further attention, particularly as the results of the present study only demonstrated trends towards significance in the relationships between perceived suffering, and caregiver depression and anxiety. However, the present results do add to a body of research to suggest that caregivers perceive higher levels of suffering and lower levels of well-being in IWDs, than IWDs self-report (e.g. Schulz *et al.*, 2013). Given the discrepancies in findings to date, further research would confirm in what circumstances the relationships between perceived suffering and caregiver outcomes are found. In

addition, further research could inform understanding of the development of these discrepancies and examine the directionality of the relationships between levels of suffering and caregivers' psychological well-being. Authors previously highlighted that the bias in suffering ratings needed to be examined in the context of factors such as diagnosis type, gender and the relationships between the IWD and caregiver (Schulz *et al.*, 2013). In the current study, only spousal co-habiting caregivers, with relatively high levels of socioeconomic status were included. These demographics have previously been shown to be important variables in caregiver depression and anxiety (e.g. Baumgarten *et al.*, 1992; Zanetti *et al.*, 1998). Research should therefore continue to explore how these and other demographic characteristics relate to the variation in the caregiver experience. This delineation of sub-groups is crucial to identifying caregiver groups that are more prone to develop psychological difficulties.

Third, the present research has begun to explore the role of caregivers' levels of empathy and satisfaction, on caregiver depression and anxiety. No direct relationships were found. The authors wonder whether this may be because empathy and satisfaction moderate the relationship between perceived suffering and caregivers' psychological outcomes. This would be in keeping with previous models of empathy and compassion fatigue (Day & Anderson, 2011; Figley & Roop, 2006; Monin & Schulz, 2009). Previous research has also indicated significant sex differences on the IRI (Davis, 1980). It may be that significant correlations were not found because results from male and female caregivers were analysed together. Further research with larger sample sizes could identify how caregivers' gender impacts on the relationship between empathy and mental health outcomes, or between satisfaction and mental health outcomes.

Finally, future research must consider using dyadic methodologies to improve understanding in the literature. As previously highlighted, the perspective of the IWD is often neglected within research, despite suggestions that much could be gained from examining IWDs' views of their illness (Cotrell & Schulz, 1993). The challenges of this must nonetheless be considered. Researchers must evaluate the validity and reliability of information from IWDs and a critical time for recruitment may therefore be during the

mild stages of dementia. Research should also consider the potential impact of participation, such as additional burden, emotional strain, time requirements and issues regarding privacy and confidentiality. Dyadic methodologies also raise challenges for recruitment, as found in the present study. The challenges of recruitment for dementia research have been discussed extensively (e.g. Connell *et al.*, 2001) and suggestions for improving recruitment have been published, particularly regarding recruitment from minority populations (Areán *et al.*, 1996; Gallagher-Thompson *et al.*, 2006). Recommendations include participants having access to regular contact with staff and feedback regarding research results (Connell *et al.*, 2001). Anecdotally, caregivers and IWDs within the current research also reported benefits from having the opportunity to discuss their experiences with an external professional. Given the existing difficulties with recruitment, this literature must be considered when designing future research in this area.

The recent growth in caregiver research now offers increased theoretical understanding of psychological outcomes in caregiving populations. However, many questions remain, particularly with regards to variables such as suffering, empathy and satisfaction. There also continues to be a pressing need for research regarding caregiver anxiety as an independent primary outcome and in the context of comorbid depression. It remains a priority to fully understand these variables, to aid the development of theoretically-based interventions for clinically depressed and anxious caregivers. The employment of longitudinal and mediational methodologies will also be imperative in interpreting directionality and causality within caregiver outcomes. The authors also urge future researchers to more widely consider the use of dyadic methodologies and existing recommendations for recruitment as discussed above.

Conflicts of Interest

None.

Acknowledgements

The authors would like to thank all of the caregivers and IWDs that agreed to take part in this study. We would also like to acknowledge Emma Law and Phil Brown at the Scottish Dementia Clinical Research Network, as well as all of the clinicians in the NHS Tayside CMHT-OPs, for their invaluable support with recruitment.

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APPENDICES

Appendix A: Systematic Review Journal Article

Appendix A1: Author Guidelines for *The International Journal of Geriatric Psychiatry*

Appendix A2: Quality Assessment Criteria

Appendix A3: Characteristics of Excluded Studies

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Appendix B: Empirical Study Journal Article

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Appendix B6: Letter of SDCRN Approval

Appendix B7: Cover Letter to Potential Participants^{*}

Appendix B8: Participant Information Sheet for the Individuals with Dementia^{*}

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Appendix B10: Participant Consent Form 1

Appendix B11: Participant Consent Form 2 – SDCRN Recruitment

Appendix B12: Participant Consent Form 2 – NHS Tayside CMHT Recruitment

Appendix B13: Letter to GP of Participants^{*}

Appendix B14: Demographics Questionnaires

Appendix B15: Hospital Anxiety and Depression Scale

Appendix B16: Suffering Scales – For the Individual with Dementia

Appendix B17: Suffering Scales – For the Partner of the Individual with Dementia

^{*} Minor modifications were made to these documents, consistent with the recruitment pathway through which contact was made with the potential participants (i.e. through the SDCRN register or through the NHS Tayside CMHTs)

Appendix B18: Scoring Guide for the Suffering Guide

Appendix B19: Interpersonal Reactivity Index

Appendix B20: Caregiver Satisfaction Scale

Appendix A1: Author Guidelines for Submissions to The International Journal of Geriatric Psychiatry



Edited By: Professor Alistair Burns, Manchester, UK

Impact Factor: 2.977

ISI Journal Citation Reports © Ranking: 2012: 6/31 (Gerontology); 17/47 (Geriatrics & Gerontology); 29/121 (Psychiatry (Social Science)); 46/135 (Psychiatry)

Online ISSN: 1099-1166

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The rapidly increasing world population of aged people has led to a growing need to focus attention on the problems of mental disorder in late life. The aim of the *International Journal of Geriatric Psychiatry* is to communicate the results of original research in the causes, treatment and care of all forms of mental disorder which affect the elderly. The Journal is of interest to psychiatrists, psychologists, social scientists, nurses and others engaged in therapeutic professions, together with general neurobiological researchers.

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Research Letters and Correspondence should be formatted in one continuous section.

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Porteus SD. 1959. *The Maze Tests and Clinical Psychology*. Pacific Books: Palo Alto.

Rabbitt PMA. 1982. How do old people know what to do next? In *Aging and Cognitive Processes*, Craik FIM, Trehub S (eds). Plenum Press: New York; 79–98.

Chou K-L, Chi I. 2004. Combined effect of vision and hearing impairment on depression in elderly Chinese. *Int J Geriatr Psychiatry* **19**: 825–832. DOI: 10.1002/gps.1174

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We recommend the use of a tool such as EndNote for reference management and formatting.

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Appendix A2: Quality Assessment Criteria

1. Study rationale: the study addresses an appropriate and clearly focused question

WC: The aims of the study are clearly stated and the context of the study is well described with a clear explanation of, and justification for, the research questions and the methods used.

AA: Research questions and objectives are outlined .

PA: Lack of clarity for research questions and objectives.

NA: No clear rationale or questions described.

2. Theoretical framework: the study was based upon a theoretical framework

WA: The study provides an explicit account of the theoretical framework and/or includes a robust literature review, which links the research to an existing body of knowledge.

AA: The study is theoretically based and includes an adequate literature review .

PA: The literature review is inadequate and the study fails to make links between existing literature and research undertaken.

NA: No clear theoretical framework is described.

3. Selection of Subjects: Well-described and justified study sampling strategy

WC: Clear rationale, justification and description of the circumstances under which the sample was recruited. Clearly defined inclusion/exclusion criteria for sample.

AA: Sampling strategy, recruitment methodology and inclusion/exclusion criteria adequately defined.

PA: Lack of clarity in description of sampling strategy, recruitment methodology and inclusion/exclusion criteria.

NA: No description regarding sampling strategy, recruitment methodology or the inclusion/exclusion criteria used.

4. Comparison group: Treatment and control groups are similar at start of trial

WC: Significant differences in demographics (e.g. age, gender), caregiving variables (e.g. relationship to individual with dementia) and baseline measures are identified and controlled for as covariates.

AA: Some significant differences are identified/ reported through comparisons and these may or may not be controlled for as covariates.

PA: Few significant differences are identified/reported through comparisons and these are not controlled for as covariates.

NA: No clear comparison between treatment and control groups.

5. Attrition rates: Description of participants lost between assessment time points

WC: Attrition rates are reported at each follow-up stage, sample numbers included in analyses are clearly identified and attrition < 20% .

AA: Attrition rates and sample numbers included in analyses not always clear and/or attrition rates of 20-39%.

PA: Attrition rates were not reported in enough detail to ascertain sample size at follow-up and /or Attrition of >40%.

NA: Attrition was not addressed.

6. Allocation Concealment Procedures: Description of Randomised assignment and concealment methods

WC: True random allocation or minimisation allocation to treatment groups is described, where the randomisation process is carried out independently of the trial research team.

AA: True random allocation or minimisation allocation is described, but the details of this process are unclear.

PA: Details of the type and procedures of random allocation are inadequately described.

7. Outcome Blinding: Investigators and outcome assessors blinded to treatment allocation

WC: Clear description is provided of assessments being completed by independent assessors blinded to group allocation and rater blinding is verified.

AA: Adequate description of assessments completed by independent assessors, blinded to group allocation, however rater blinding is not verified.

PA: Poor description of blinding procedures where assessor is not described or not independent.

NA: Blinding not reported.

8. Intervention Description: Intervention delivered is clearly defined and appropriate

WC: Treatment well-described and adherence to treatment protocol or treatment quality is assessed.

AA: Treatment is adequately described (or adequate reference is made to treatment protocol in the existing literature) and assessment of adherence or quality may or may not be completed.

PA: Treatment is poorly described and few references to existing literature are provided.

NA: No clear description of the treatment is provided.

9. Outcome measures: robust measures used and validity/reliability described (only measure of anxiety assessed here)

WC: Standardised measures are used and robust validity and reliability are clearly described.

AA: Standardised measures are used and references to reliability and validity are described.

PA: The outcomes are defined but with little description of the measures or their reliability and validity.

NA: Idiosyncratic assessment of symptoms is used.

10. Data analysis: intention to treat methodology of data analysis was used

WC: Analysis includes all those participants as randomised (sometimes referred to as an intention to treat analysis) and an adequate investigation of drop-outs from assessment is included where attrition is >20%.

AA: Analysis includes all those participants as randomised (sometimes referred to as an intention to treat analysis).

NA: Analysis does not include all participants as randomised.

11. Sample size: sample size provided sufficient power for statistical analysis undertaken

WC: Sample size calculation described and final sample size provided sufficient power for the statistical analysis undertaken.

AA: No calculation described and sample size may not provide sufficient statistical power for analysis undertaken. However implications for this are discussed.

PA: No calculation described and sample size may not provide sufficient statistical power for analyses undertaken. Limitations are not discussed.

12. Study Limitations: Limitations of the research are acknowledged and discussed

WC: Study and methodology limitations are discussed in full with consideration of the impact these may have had on the validity of the findings and comparisons to existing literature in the area.

AA: Discussion of study limitations is adequate in enabling the reader to identify the potential impact on study findings.

PA: Discussion of study limitations is inadequate in enabling the reader to identify the potential impact on study findings.

NA: Study limitations not identified by authors.

Scoring Guide:

Well covered (WC): 3 points

Adequately addressed (AA): 2 points

Poorly addressed (PA): 1 point

Not addressed (NA): 0 points

Appendix A3: Characteristics of Excluded Studies

| Study | Reason for Exclusion |
|-------------------|---|
| Au 2010 | Anxiety not measured as an outcome |
| Ávila 2004 | No RCT |
| Baker 2012 | No RCT |
| Bank 2006 | No RCT |
| Benson 2013 | No RCT |
| Berger 2004 | Anxiety not measured as an outcome |
| Black 2013 | Anxiety not measured as an outcome |
| Bormann 2009 | No RCT |
| Bottino 2002 | No RCT |
| Burns 2010 | Insufficient data in article |
| Brodaty 2009 | Anxiety not measured as an outcome |
| Callahan 2006 | Anxiety not measured as an outcome |
| Camic 2013 | No RCT |
| Challis 2002 | No RCT |
| Charlesworth 2008 | Same data reported in included paper |
| Chiu 2009 | No RCT |
| Choi 2009 | No RCT |
| Chow 2005 | No intervention described |
| Clancy 2011 | No RCT |
| Clare 2010 | Intervention targeted care recipient |
| Clark 2000 | Not meeting inclusion criteria for participants |
| Coen 2011 | Not meeting inclusion criteria for participants |
| Coon 2003 | Anxiety not measured as an outcome |
| Cox 1997 | No RCT |
| Dang 2008 | No RCT |
| De Rotrou 2011 | Anxiety not measured as an outcome |
| Demiris 2007 | No RCT |
| Devor 2008 | No RCT |
| Donorfio 2010 | Not meeting inclusion criteria for participants |

| Study | Reason for Exclusion |
|-----------------|---|
| Eisdorfer 2003 | Anxiety not measured as an outcome |
| Elliott 2010 | Anxiety not measured as an outcome |
| Epstein 2011 | Not meeting inclusion criteria for participants |
| Farran 2008 | No RCT |
| Fialho 2012 | No RCT |
| Fisher 2001 | No RCT |
| Forstmeier 2011 | No RCT |
| Garand 2002 | No RCT |
| Garand 2013 | Not meeting inclusion criteria for participants |
| Gerdner 1996 | Anxiety not measured as an outcome |
| Gitlin 2003 | Anxiety not measured as an outcome |
| Glueckauf 2005 | No RCT |
| Glueckauf 2007 | No RCT |
| Glueckauf 2009 | No RCT |
| Gormley 2000 | No RCT |
| Hamill 2011 | No RCT |
| Haupt 2000 | No RCT |
| Hepburn 2005 | Anxiety not reported as an outcome |
| Hergueta 2010 | Anxiety not measured as an outcome |
| Hilgeman 2007 | Anxiety not measured as an outcome |
| Hirano 2011 | Anxiety not measured as an outcome |
| Hopkins 2005 | No RCT |
| Hoppes 2012 | No RCT |
| Hosaka 1999 | No RCT |
| Hosaka 2003 | No RCT |
| Hummel 2013 | Not meeting inclusion criteria for participants |
| Irwin 2013 | No RCT |
| Jacobs 2011 | No RCT |
| Johnson 2013 | No RCT |
| Johnson 1989 | No RCT |

| Study | Reason for Exclusion |
|----------------------|---|
| Joling 2013 | Anxiety not reported as an outcome |
| Kaplan 1995 | No RCT |
| Keady 1995 | No intervention described |
| Kim 2012 | No RCT |
| Knapp 2013 | Anxiety not reported as an outcome |
| Kurylo 2011 | No RCT |
| Kuzu 2005 | No RCT |
| Lai 2013 | No RCT |
| Lavoie 2005 | No RCT |
| Leone 2014 | No RCT |
| Lewis 2009 | No RCT |
| Li 2012 | Not meeting inclusion criteria for participants |
| Livingston 2008 | No intervention described |
| Lopez 2007 | Not meeting inclusion criteria for participants |
| Lopez 2008 | Not meeting inclusion criteria for participants |
| Los Angeles 2012 | No RCT |
| Maci 2012 | Anxiety not measured as an outcome |
| Mackenzie 2013 | No RCT |
| MacNeil 2013 | No RCT |
| Mahoney 2008 | No RCT |
| Martin Carrasco 2009 | Anxiety not measured as an outcome |
| Martire 2010 | Not meeting inclusion criteria for participants |
| Marziali 2011 | No RCT |
| Måvall 2007 | No RCT |
| McHugh 2011 | No RCT |
| McKechnie 2014 | No RCT |
| Meeuwssen 2012 | Intervention targeted care recipient |
| Mensie 2010 | No intervention described |
| Millán-Calenti 2000 | No RCT |
| Mioshi 2013 | No RCT |

| Study | Reason for Exclusion |
|------------------------|---|
| Mittleman 2008 | Anxiety not measured as an outcome |
| Mizuno 1999 | Not meeting inclusion criteria for participants |
| Moniz-Cook 2008 | No RCT |
| Mossello 2007 | Anxiety not measured as an outcome |
| Narme 2014 | Intervention targeted care recipient |
| Negri 2013 | Conference abstract only |
| Nichols 2013 | No RCT |
| Oken 2010 | Anxiety not measured as an outcome |
| Ott 2010 | No RCT |
| Robinson 2011 | No RCT |
| Rodriguez-Sanchez 2013 | Not meeting inclusion criteria for participants |
| Salfi 2005 | No RCT |
| Santos 2013 | No RCT |
| Schulz 2004 | No RCT |
| Shaw 2012 | No RCT |
| Smith 2006 | Not meeting inclusion criteria for participants |
| Sorocco 2013 | No RCT |
| Spector 2003 | Intervention targeted care recipient |
| Spijker 2011 | Anxiety not measured as an outcome |
| Stevenson 2012 | No intervention described |
| Stolley 2002 | No RCT |
| Strawn 1998 | No RCT |
| Teri 2005 | Anxiety not measured as an outcome |
| Topcu 2011 | No RCT |
| Tremont 2008 | Anxiety not measured as an outcome |
| Van der Roest 2010 | No RCT |
| Vazquez-Gonzalez 2013 | Not meeting inclusion criteria for participants |
| Vicente 2009 | No RCT |
| Villareal-Reyna 2012 | No RCT |
| Waelde 2004 | No RCT |

| Study | Reason for Exclusion |
|---------------|--------------------------------------|
| Wells 1987 | Intervention targeted care recipient |
| Wilkins 1999 | No RCT |
| Williams 2013 | No RCT |
| Williams 2010 | No RCT |
| Woods 2003 | No RCT |
| Woods 2009 | Same data reported in included paper |
| Zank 2002 | No RCT |
| Zarit 2001 | No intervention described |

Appendix A4: References of Excluded Studies

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Appendix B1: Author Guidelines for Submissions to Psychology and Aging



Editor: Ulrich Mayr, PhD

ISSN: 0882-7974

eISSN: 1939-1498

Published: quarterly, beginning in March

ISI Impact Factor: 3.089

Gerontology : 4 of 30

Instructions to Authors

Prior to submission, please carefully read and follow the submission guidelines detailed below. Manuscripts that do not conform to the submission guidelines may be returned without review.

Submission

Submit manuscripts electronically through the Manuscript Submission Portal (.rtf, .doc, or .pdf files).

Ulrich Mayr Department of Psychology University of Oregon Eugene, OR
General correspondence may be directed to the Editor's Office.

In addition to addresses and phone numbers, please supply email addresses and fax numbers, if available, for potential use by the editorial office and later by the production office.

Masked Review Policy

Masked reviews are optional, and authors who wish masked reviews must specifically request them at submission. Authors requesting masked review should make every effort to see that the manuscript itself contains no clues to their identities. Authors' names, affiliations, and contact information should be included only in the cover letter.

If your manuscript was mask reviewed, please ensure that the final version for production includes a byline and full author note for typesetting.

Length

Manuscripts should not exceed 8,000 words (approximately 27 double-spaced pages in 12-point Times New Roman font). Shorter manuscripts are equally welcomed.

The word count does not include references, tables, and figures. If you feel that you need extra space, please contact the editor. For example, you may have a complex methodology or statistical approach or a new theoretical framework that requires more text.

Please include the word count for the main text below the keywords.

Brief Reports

The Brief Report format is designated for particularly "crisp," theoretically noteworthy contributions that meet highest methodological standards. Use 12-point Times New Roman type and 1-inch (2.54-cm) margins; include an abstract of 75–100 words; do not exceed 265 lines of text, not including references; and typically include no more than two tables or figures.

Manuscript Preparation

Prepare manuscripts according to the *Publication Manual of the American Psychological Association* (6th edition). Manuscripts may be copyedited for bias-free language (see Chapter 3 of the *Publication Manual*).

Review APA's Checklist for Manuscript Submission before submitting your article.

Double-space all copy. Other formatting instructions, as well as instructions on preparing tables, figures, references, metrics, and abstracts, appear in the *Manual*.

Below are additional instructions regarding the preparation of display equations, computer code, and tables.

Display Equations

We strongly encourage you to use MathType (third-party software) or Equation Editor 3.0 (built into pre-2007 versions of Word) to construct your equations, rather than the equation support that is built into Word 2007 and Word 2010. Equations composed with the built-in Word 2007/Word 2010 equation support are converted to low-resolution graphics when they enter the production process and must be rekeyed by the typesetter, which may introduce errors.

To construct your equations with MathType or Equation Editor 3.0:

Go to the Text section of the Insert tab and select Object.

Select MathType or Equation Editor 3.0 in the drop-down menu.

If you have an equation that has already been produced using Microsoft Word 2007 or 2010 and you have access to the full version of MathType 6.5 or later, you can convert this equation to MathType by clicking on MathType Insert Equation. Copy the equation from Microsoft Word and paste it into the MathType box. Verify that your equation is correct, click File, and then click Update. Your equation has now been inserted into your Word file as a MathType Equation. Use Equation Editor 3.0 or MathType only for equations or for formulas that cannot be produced as Word text using the Times or Symbol font.

Computer Code

Because altering computer code in any way (e.g., indents, line spacing, line breaks, page breaks) during the typesetting process could alter its meaning, we treat computer code differently from the rest of your article in our production process. To that end, we request separate files for computer code.

In Online Supplemental Material We request that runnable source code be included as supplemental material to the article. For more information, visit [Supplementing Your Article With Online Material](#).

In the Text of the Article If you would like to include code in the text of your published manuscript, please submit a separate file with your code exactly as you want it to appear, using Courier New font with a type size of 8 points. We will make an image of each segment of code in your article that exceeds 40 characters in length. (Shorter snippets of code that appear in text will be typeset in Courier New and run in with the rest of the text.) If an appendix contains a mix of code and explanatory text, please submit a file that contains the entire appendix, with the code keyed in 8-point Courier New.

Tables

Use Word's Insert Table function when you create tables. Using spaces or tabs in your table will create problems when the table is typeset and may result in errors.

Submitting Supplemental Materials

APA can place supplemental materials online, available via the published article in the PsycARTICLES® database. Please see [Supplementing Your Article With Online Material](#) for more details.

Abstract and Keywords

All manuscripts must include an abstract containing a maximum of 250 words typed on a separate page. After the abstract, please supply up to five keywords or brief phrases.

References

List references in alphabetical order. Each listed reference should be cited in text, and each text citation should be listed in the References section.

Examples of basic reference formats:

Journal Article: Hughes, G., Desantis, A., & Waszak, F. (2013). Mechanisms of intentional binding and sensory attenuation: The role of temporal prediction, temporal control, identity prediction, and motor prediction. *Psychological Bulletin*, 139, 133–151. <http://dx.doi.org/10.1037/a0028566>

Authored Book: Rogers, T. T., & McClelland, J. L. (2004). *Semantic cognition: A parallel distributed processing approach*. Cambridge, MA: MIT Press.

Chapter in an Edited Book: Gill, M. J., & Sypher, B. D. (2009). Workplace incivility and organizational trust. In P. Lutgen-Sandvik & B. D. Sypher (Eds.), *Destructive organizational communication: Processes, consequences, and constructive ways of organizing* (pp. 53–73). New York, NY: Taylor & Francis.

Figures

Graphics files are welcome if supplied as Tiff or EPS files. Multipanel figures (i.e., figures with parts labeled a, b, c, d, etc.) should be assembled into one file.

The minimum line weight for line art is 0.5 point for optimal printing.

For more information about acceptable resolutions, fonts, sizing, and other figure issues, please see the general guidelines.

When possible, please place symbol legends below the figure instead of to the side. APA offers authors the option to publish their figures online in color without the costs associated with print publication of color figures.

The same caption will appear on both the online (color) and print (black and white) versions. To ensure that the figure can be understood in both formats, authors should add alternative wording (e.g., "the red (dark gray) bars represent") as needed.

For authors who prefer their figures to be published in color both in print and online, original color figures can be printed in color at the editor's and publisher's discretion provided the author agrees to pay:

- \$900 for one figure
- An additional \$600 for the second figure
- An additional \$450 for each subsequent figure

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On advice of counsel, APA may decline to publish any image whose copyright status is unknown.

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APA policy prohibits an author from submitting the same manuscript for concurrent consideration by two or more publications.

See also APA Journals® Internet Posting Guidelines.

APA requires authors to reveal any possible conflict of interest in the conduct and reporting of research (e.g., financial interests in a test or procedure, funding by pharmaceutical companies for drug research).

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Authors of accepted manuscripts are required to transfer the copyright to APA.

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Ethical Principles

It is a violation of APA Ethical Principles to publish "as original data, data that have been previously published" (Standard 8.13).

In addition, APA Ethical Principles specify that "after research results are published, psychologists do not withhold the data on which their conclusions are based from other competent professionals who seek to verify the substantive claims through reanalysis and who intend to use such data only for that purpose, provided that the confidentiality of the participants can be protected and unless legal rights concerning proprietary data preclude their release" (Standard 8.14).

APA expects authors to adhere to these standards. Specifically, APA expects authors to have their data available throughout the editorial review process and for at least 5 years after the date of publication.

Authors are required to state in writing that they have complied with APA ethical standards in the treatment of their sample, human or animal, or to describe the details of treatment.

[Download Certification of Compliance With APA Ethical Principles Form \(PDF, 26KB\)](#)

The APA Ethics Office provides the full Ethical Principles of Psychologists and Code of Conduct electronically on its website in HTML, PDF, and Word format. You may also request a copy by emailing or calling the APA Ethics Office (202-336-5930). You may also read "Ethical Principles," December 1992, *American Psychologist*, Vol. 47, pp. 1597–1611.

Other Information

[Appeals Process for Manuscript Submissions](#)
[Preparing Auxiliary Files for Production](#)
[Document Deposit Procedures for APA Journals](#)

Appendix B2: Letter of NHS Ethics Committee Approval

EoSRES



Research Ethics Service

East of Scotland Research Ethics Service (EoSRES) REC 1

Tayside Medical Sciences Centre (TASC)
Residency Block C, Level 3
Ninewells Hospital & Medical School
George Pirie Way
Dundee DD1 9SY

Miss Rebecca Slade
Trainee Clinical Psychologist
University of Edinburgh / NHS Tayside
Dundee Adult Psychological Therapies Service
7 Dudhope Terrace
Dundee
DD3 6HG

Date: 09 May 2013
Your Ref: LR/13/ES/0019
Our Ref: Mrs Lorraine Reilly
Enquiries to: Ninewells extension: 2283848
Extension: 01382 383848
Direct Line: Eosres.tayside@nhs.net
Email:

Dear Miss Slade

Study title: Similarities and Differences in the Experiences of People with Dementia and their Partners
REC reference: 13/ES/0019
Protocol number: N/A
IRAS project ID: 112363

Thank you for your letter received on 07 May 2013. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 25 March 2013

Documents received

The documents received were as follows:

| Document | Version | Date |
|--|---------|---------------|
| Participant Consent Form | 5 | 07 April 2013 |
| Participant Information Sheet: Highlighted changes | 5 | 07 April 2013 |
| Participant Information Sheet: Highlighted changes | 5 | 07 April 2013 |
| Response to Request for Further Information | | 05 May 2013 |

Approved documents

The final list of approved documentation for the study is therefore as follows:

| Document | Version | Date |
|------------------------------------|---------|-----------------|
| Evidence of insurance or indemnity | | 22 June 2012 |
| GP/Consultant Information Sheets | 3 | 04 January 2013 |
| Investigator CV | | |
| Investigator CV | | |
| Investigator CV | | |

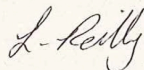


| | | |
|---|---|------------------|
| Investigator CV | | |
| Letter of invitation to participant | 4 | 04 January 2013 |
| Other: PPI Response | | 30 October 2012 |
| Participant Consent Form: Consent Form 1 | 4 | 04 January 2013 |
| Participant Consent Form | 5 | 07 April 2013 |
| Participant Information Sheet: Highlighted changes | 5 | 07 April 2013 |
| Participant Information Sheet: Highlighted changes | 5 | 07 April 2013 |
| Protocol | 4 | 31 January 2013 |
| Questionnaire: ACE-II | | |
| Questionnaire: Caregiving Satisfaction Scale | | |
| Questionnaire: Demographic Questionnaire | 4 | 04 January 2013 |
| Questionnaire: HADS | | |
| Questionnaire: Interpersonal Reactivity Index | 3 | 04 January 2013 |
| Questionnaire: Suffering Scale For the Partner | 3 | 04 January 2013 |
| Questionnaire: Suffering Scale for the Person with Dementia | 3 | 04 January 2013 |
| REC application | | 18 February 2013 |
| Response to Request for Further Information | | 05 May 2013 |
| Summary/Synopsis | 2 | 03 December 2012 |
| Summary/Synopsis | 2 | 03 December 2012 |
| Summary/Synopsis | 2 | 03 December 2012 |

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

| | |
|------------|--|
| 13/ES/0019 | Please quote this number on all correspondence |
|------------|--|

Yours sincerely





Mrs Lorraine Reilly
Senior Co-ordinator

Eosres.tayside@nhs.net

Copy to: Ms Marianne Laird
NHS Tayside R & D Office



Appendix B3: Letter of NHS Ethics Committee Approval for Amendment 1



East of Scotland Research Ethics Service (EoSRES) REC 1
Tayside Medical Sciences Centre (TASC)
Residency Block C, Level 3
Ninewells Hospital & Medical School
George Pirie Way
Dundee DD1 9SY

Miss Rebecca Slade
Trainee Clinical Psychologist
University of Edinburgh / NHS Tayside
Dundee Adult Psychological Therapies Service
7 Dudhope Terrace
Dundee, DD3 6HG

Date: 11 July 2013
Your Ref:
Our Ref: LR/DL/13/ES/0019
Enquiries to: Mrs Lorraine Reilly
Extension: Ninewells extension: 83878
Direct Line: 01382 383878
Email: eosres.tayside@nhs.net

Dear Miss Slade

Study title: Similarities and Differences in the Experiences of People with Dementia and their Partners
REC reference: 13/ES/0019
Protocol number: N/A
Amendment number: AM01 (For REC Reference Only)
Amendment date: 25 June 2013
IRAS project ID: 112363

The above amendment was reviewed 09 July 2013 by the Sub-Committee in correspondence.

Ethical opinion

No ethical issues noted.

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.


Approved documents

The documents reviewed and approved at the meeting were:

| Document | Version | Date |
|---|---------|--------------|
| Notice of Substantial Amendment (non-CTIMPs) | AM01 | 25 June 2013 |
| Participant Information Sheet: For the Partner | 6 | 19 June 2013 |
| Participant Information Sheet: For the Person with Dementia | 6 | 19 June 2013 |
| CV - Dr David Gillanders | | 15 May 2013 |

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.



R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

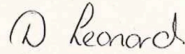
The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

13/ES/0019:

Please quote this number on all correspondence

Yours sincerely



per **Dr Lynda Cochrane**
Alternate Vice-Chair

E-mail: ecosres.tayside@nhs.net

Enclosures:

List of names and professions of members who took part in the review

Copy to:

NHS Tayside R&D Office
Ms Marianne Laird, University of Edinburgh



Appendix B4: Letter of NHS Ethics Committee Approval for Amendment 2

EoSRES



Research Ethics Service

East of Scotland Research Ethics Service (EoSRES) REC 1

Tayside Medical Sciences Centre (TASC)
Residency Block C, Level 3
Ninewells Hospital & Medical School
George Pirie Way
Dundee DD19SY

Miss Rebecca Slade
Trainee Clinical Psychologist
University of Edinburgh / NHS Tayside
Dundee Adult Psychological Therapies Service
7 Dudhope Terrace
Dundee
DD3 6HG

Date: 26 November 2013
Your Ref:
Our Ref: LR/13/ES/0019
Enquiries to: Mrs Lorraine Reilly
Direct Line: 01382 383878
Email: eosres.tayside@nhs.net

Dear Miss Slade

| | |
|--------------------------|---|
| Study title: | Similarities and Differences in the Experiences of People with Dementia and their Partners |
| REC reference: | 13/ES/0019 |
| Protocol number: | N/A |
| Amendment number: | AM02 (for REC reference only) |
| Amendment date: | 19 November 2013 |
| IRAS project ID: | 112363 |

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

There were no ethical issues noted.

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

| Document | Version | Date |
|---|---------|------------------|
| Covering Letter | | 19 November 2013 |
| Notice of Substantial Amendment (non-CTIMPs) | AM02 | 19 November 2013 |
| GP/Consultant Information Sheets | 1 | 31 October 2013 |
| Participant Information Sheet: For the Partner - Angus | 1 | 31 October 2013 |
| Participant Information Sheet: For the Person with Dementia - Angus | 1 | 31 October 2013 |
| Participant Consent Form: Angus (For the Person with Dementia) | 1 | 31 October 2013 |
| Protocol | 6 | 31 October 2013 |



Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

13/ES/0019

Please quote this number on all correspondence

Yours sincerely



pp

Dr Lynda Cochrane
Alternate Vice-chair

eosres.tayside@nhs.net

Enclosures:

List of names and professions of members who were present at the meeting and those who submitted written comments

Copy to:

NHS Tayside R&D office
Ms Marianne Laird



Appendix B5: Letter of NHS Ethics Committee Approval for Amendment 3

EoSRES



East of Scotland Research Ethics Service (EoSRES) REC 1

Tayside Medical Sciences Centre (TASC)
Residency Block C, Level 3
Ninewells Hospital & Medical School
George Pirie Way
Dundee DD1 9SY

Miss Rebecca Slade
Trainee Clinical Psychologist
University of Edinburgh / NHS Tayside
Dundee Adult Psychological Therapies Service
7 Dudhope Terrace
Dundee
DD3 6HG

Date: 06 May 2014
Your Ref:
Our Ref: LR/DL/13/ES/0019
Enquiries to: Mrs Lorraine Reilly
Extension: Ninewells extension: 83878
Direct Line: 01382 383878
Email: eosres.tayside@nhs.net

Dear Miss Slade

Study title: Similarities and Differences in the Experiences of People with Dementia and their Partners
REC reference: 13/ES/0019
Protocol number: N/A
Amendment number: AM03 (For REC Reference Only)
Amendment date: 28 April 2014
IRAS project ID: 112363

The above amendment was reviewed on 06 May 2014 by the Sub-Committee in correspondence.

Ethical opinion

No ethical issues noted.

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

| Document | Version | Date |
|--|---------|---------------|
| Protocol | 7 | 10 April 2014 |
| Notice of Substantial Amendment (non-CTIMPs) | AM03 | 28 April 2014 |

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.



Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

13/ES/0019:

Please quote this number on all correspondence

Yours sincerely



**for Dr Carol MacMillan
Chair**

E-mail: eosres.tayside@nhs.net

Enclosures: List of names and professions of members who took part in the review

Copy to: NHS Tayside R&D Office
Ms Marianne Laird



Appendix B6: Letter of Scottish Dementia Clinical Research

Psychiatry of Old Age
Murray Royal Hospital
Muirhall Road
Perth
PH2 7BH
Telephone Number: 01738 562322
Fax Number: 01738 562441



Miss Rebecca Slade
NHS Tayside Psychological Therapies Service
7 Dudhope Terrace
Dundee
DD3 6HG

Our Ref
Enquiries to
Direct Line
E mail

NAN 26
Philip Brown, Administrator
01738 562322
philipbrown1@nhs.net

13th May, 2013

Dear Miss Slade

We have considered your study '**Similarities and Differences in the Experiences of People with Dementia and their Partners**' for adoption to the Scottish Dementia Clinical Research Network.

We have pleasure in informing you that the network has approved adoption of your study for the following support:

- Access to patient and carer data

We wish you every success in your project.

We would like to include a brief summary of your study and contact details on our website. Please let me know if this is not acceptable.

Please do not hesitate to contact me for further clarification and assistance when the time arises at emma.law@nhs.net.

Yours sincerely

EMMA LAW
Manager
Scottish Dementia Clinical Research Network

cc Dr Fiona MacLeod

Network Approval

Appendix B7: Cover Letter to Potential Participants

Similarities and Differences in the Experiences of People with Dementia and their Partners
Cover Letter Version 4, 04/01/2013



Similarities and Differences in the Experiences of People with Dementia and their Partners

Dear <<Name>> ,

My name is Rebecca Slade. I am training to be a Clinical Psychologist at the University of Edinburgh and work for NHS Tayside. As part of my training, I am carrying out a study looking at the impact of dementia on individuals and their partners. I would like to invite you to take part in this study.

I would first like to tell you why the study is being carried out and what you would be asked to do if you decide to participate in the study.

Please read the following information carefully or be sure that someone reads it to you. Please also feel free to ask any questions you may have about the study.

It is important that you are aware that you do not need to make a decision straight away, and you can also talk to your friends and family about the study if you wish.

Thank you for taking the time to read this.

Yours sincerely,

Rebecca Slade
Trainee Clinical Psychologist
University of Edinburgh / NHS Tayside
rebeccaslade@nhs.net
01356 692 806

Appendix B8: Participant Information Sheet for the Individuals with Dementia

Similarities and Differences in the Experiences of People with Dementia and their Partners
Participant Information Sheet (For the Person with Dementia) Version 6, 19/06/2013



Similarities and Differences in the Experiences of People with Dementia and their Partners

PARTICIPANT INFORMATION SHEET FOR INDIVIDUAL WITH DEMENTIA

My name is Rebecca Slade. I am required to undertake a project as part of my course and invite you to take part in the following study. However, before you decide to do so, I need to be sure that you understand firstly why I am doing it, and secondly what it would involve if you agreed. I am therefore providing you with the following information.

Please read it carefully and be sure to ask any questions you might have and, if you want, discuss it with others including your friends and family. I will do my best to explain the project to you and provide you with any further information you may ask for now or later.

What is the study about?

Following the diagnosis of dementia, a person can often experience a number of changes in their daily life, which can have an effect on how they feel physically and emotionally. This can also sometimes lead to changes in the life of the individual's partner. The aim of the research is to increase the understanding of the experiences of people with dementia and their partners, and to identify what can help maintain well-being. It is hoped that this research will help contribute to improvements in services for those with dementia and their partners.

Why have I been invited to participate?

You are being asked to take part in this study as you are registered with the Scottish Dementia Clinical and Research Network database. If you choose to take part in this research, it will involve answering some questions about your experiences with having dementia. It will also look at how these are similar or different from how your partner has perceived your experience of dementia.

What will I be asked to do?

If you are interested in knowing more about this research, we will arrange an initial meeting at a day, time and location that is convenient for you and your partner. At this meeting, we can talk more about the study and I will answer any questions either of you may have. You will then have up to a week to decide if you would like to take part or not. If you decide to take part, I will ask you to sign and write your name on a consent form. This says that you agree to take part in the study.

If you agree to talk part, we will arrange to begin the study. During this meeting, I will ask you some questions about your experience of dementia. This will not take more than 45 minutes and you will be offered breaks throughout. If you feel tired or need to stop early, it will also be possible to arrange a further meeting to finish the questions. If there are any questions you don't want to answer, that's OK, you don't have to take part.

The information that I collect from you will be kept secure. This means that your name and contact details will not be available to anyone other than myself and my supervisors.

Do I have to take part in the study?

No, it's up to you if you take part in the study or not. Your participation is entirely voluntary. If you do not want to take part, this will not affect the care you receive from any NHS service now or in the future.

You can also change your mind about your participation at any time during the study and you do not have to give a reason. You also have the right to ask that any information collected up to that point be withdrawn from the study and destroyed.

What are the possible benefits of taking part?

There is unlikely to be any particular direct benefit to you but you may feel your participation will contribute to a greater understanding of dementia and the impact that it can have on individuals and their partners. We hope this will allow us to provide future recommendations at a local and national level about how older people services can be a better support for individuals with dementia and their partners.

What are the disadvantages or risks of taking part?

There is a risk that you may feel fatigued or would like to stop earlier. If this happens, we can arrange a further meeting to suit you. We will not meet more than 3 times in total. Unfortunately I am unable to offer any payment, reimbursement of expenses or any other incentives for taking part in this study. However, to minimise expenses for yourself, it is possible to arrange our meetings to take place somewhere convenient for you, such as your home.

Will my taking part in the study be kept confidential?

Only my supervisors (Dr Fiona Macleod, Dr David Gillanders and Professor Kevin Power) and I will be allowed to see the information that I collect from you. Once you have completed all the questions, your name and any identifiable information will be removed. This means that no one will be able to tell that it's you. With your consent, we will also inform your General Practitioner (GP) that you are taking part in this study.

During the study, if you tell me anything that makes me think that you are at risk of harm, or others around you are at risk, I will have to tell someone however. This is to make sure that you and other people are safe. This will either be the person who told you about the study in the first place or a Clinical Psychologist working for NHS Tayside. If this were to happen, I would inform you of it first and discuss what to do next with you.

Will I find out the results of the study?

It is your decision if you would like to know what I find out from the research. If you wish to know the results of the study, I can either provide you with a written summary of the study, or we can arrange a meeting where I can tell you the results.

What will happen to the results of the study?

I will share the results of the study with my supervisors. I will also write up the results of the study for submission as part of my training to be a Clinical Psychologist, and for publication in a scientific journal. These results will be entirely anonymous however, and no participants will be identifiable by name.

Who is organising the research and why?

I am training to be a Clinical Psychologist at the University of Edinburgh and work for NHS Tayside. I am carrying out this research as part of my training to become a Clinical Psychologist.

Who has reviewed the study?

The study proposal has been reviewed by the University of Edinburgh Doctorate in Clinical Psychology course and by my supervisors. NHS management approval and approval from the Scottish Dementia Clinical and Research Network have also been obtained.

The East of Scotland Research Ethics Committee REC 1, which has responsibility for scrutinising all proposals for medical research on humans in Tayside, has examined the proposal and has raised no objections from the point of view of medical ethics. It is a requirement that your records in this research, together with any relevant records, be made available for scrutiny by monitors from the University of Edinburgh and NHS Tayside, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

I want to know more about the study. What should I do?

If you wish to take part, or would like to meet with me to talk more about the study, please fill in your name and phone number on Consent Form 1 and we can arrange a time and place to meet to discuss the study further or to start the research. You can also phone to talk to me about the study. **My phone number is: 01356 692 806.**

I don't agree with the study. What should I do?

If you believe that you have been harmed in any way by taking part in this study, you have the right to pursue a complaint and seek any resulting compensation through the University of Edinburgh who are acting as the research sponsor. Details about this are available from the research team.

Also, as a patient of the NHS, you have the right to pursue a complaint through the usual NHS process. To do so, you can submit a written complaint to the Patient Liaison Manager, Complaints Office, Ninewells Hospital, Dundee, DD1 9SY (Freephone: 0800 027 5507).

Note that the NHS has no legal liability for non-negligent harm. However, if you are harmed and this is due to someone's negligence, you may have grounds for a legal action against NHS Tayside but you may have to pay your legal expenses.

If you don't agree with any part of this study, you can also speak to:

My supervisor: Dr Fiona Macleod, Consultant Clinical Psychologist,
Susan Carnegie Centre, Stracathro Hospital,
By Brechin, DD9 7QA
Phone: 01356 692 806

Or talk to an independent NHS advisor:
Dr. Claire Campbell, Clinical Psychologist
NHS Tayside - Dundee Psychological Therapies
Carseview, 4 Tom McDonald Avenue, Dundee,
DD2 1NH
Phone: 01382 346055

Thank you for taking the time to read this information sheet and considering whether you would like to participate in this research.

If you wish to take part in the study, please sign the attached consent form and send it back in the self-addressed stamped envelope.

This information sheet is for you to keep.

Appendix B9: Participant Information Sheet for the Partners of the Individuals with Dementia

Similarities and Differences in the Experiences of People with Dementia and their Partners
Participant Information Sheet (For the Partner) Version 6, 19/06/2013



Similarities and Differences in the Experiences of People with Dementia and their Partners

PARTICIPANT INFORMATION SHEET FOR THE PARTNER OF THE INDIVIDUAL WITH DEMENTIA

My name is Rebecca Slade. I am required to undertake a project as part of my course and invite you to take part in the following study. However, before you decide to do so, I need to be sure that you understand firstly why I am doing it, and secondly what it would involve if you agreed. I am therefore providing you with the following information.

Please read it carefully and be sure to ask any questions you might have and, if you want, discuss it with others including your friends and family. I will do my best to explain the project to you and provide you with any further information you may ask for now or later.

What is the study about?

Following the diagnosis of dementia, a person can often experience a number of changes in their daily life, which can have an effect on how they feel physically and emotionally. The diagnosis of dementia can sometimes lead to changes in the life of the individual's partner, and may also lead to changes in how the partner feels physically and emotionally. The aim of the research is to increase the understanding of the experiences of people with dementia and their partners, and to identify what can help maintain well-being. It is hoped that this research will help contribute to improvements in services for those with dementia and their partners.

Why have I been invited to participate?

You are being asked to take part in this study as you are registered with the Scottish Dementia Clinical and Research Network database. If you choose to take part in this research, it will involve answering some questions about your experiences with having a partner with dementia. It will also look at your perceptions of your partner's experiences of having dementia, and how these are similar or different from how your partner describes their own experiences.

What will I be asked to do?

If you are interested in knowing more about this research, we will arrange an initial meeting at a day, time and location that is convenient for you and your partner. At this meeting, we can talk more about the study and I will answer any questions either of you may have.

You will then have up to a week to decide if you would like to take part or not. If you decide to take part, I will ask you to sign and write your name on a consent form. This says that you agree to take part in the study.

If you agree to talk part, we will arrange to begin the study. During this meeting, I will ask you some questions about your experience as the partner of someone with dementia. I will also ask you some questions about the effect that the diagnosis of dementia has had on both the life of your partner and on own your life. This will not take more than 45 minutes and you will be offered breaks throughout. If you feel tired or need to stop early, it will also be possible to arrange a further meeting to finish the questions. If there are any questions you don't want to answer, that's OK, you don't have to take part.

The information that I collect from you will be kept secure. This means that your name and contact details will not be available to anyone other than myself and my supervisors.

Do I have to take part in the study?

No, it's up to you if you take part in the study or not. Your participation is entirely voluntary. If you do not want to take part, this will not affect the care you receive from any NHS service now or in the future.

You can also change your mind about your participation at any time during the study and you do not have to give a reason. You also have the right to ask that any information collected up to that point be withdrawn from the study and destroyed.

What are the possible benefits of taking part?

There is unlikely to be any particular direct benefit to you but you may feel your participation will contribute to a greater understanding of dementia and the impact that it can have on individuals and their partners. We hope this will allow us to provide future recommendations at a local and national level about how older people services can be a better support for individuals with dementia and their partners.

What are the disadvantages or risks of taking part?

There is a risk that you may feel fatigued or would like to stop earlier. If this happens, we can arrange a further meeting to suit you. We will not meet more than 3 times in total. Unfortunately I am unable to offer any payment, reimbursement of expenses or any other incentives for taking part in this study. However, to minimise expenses for yourself, it is possible to arrange our meetings to take place somewhere convenient for you, such as your home.

Will my taking part in the study be kept confidential?

Only my supervisors (Dr Fiona Macleod, Dr David Gillanders and Professor Kevin Power) and I will be allowed to see the information that I collect from you. Once you have completed all the questions, your name and any identifiable information will be removed. This means that no one will be able to tell that it's you. With your consent, we will also inform your General Practitioner (GP) that you are taking part in this study.

During the study, if you tell me anything that makes me think that you are at risk of harm, or others around you are at risk, I will have to tell someone however. This is to make sure that you and other people are safe. This will either be the person who told you about the study in the first place or a Clinical Psychologist working for NHS Tayside. If this were to happen, I would inform you of it first and discuss what to do next with you.

Will I find out the results of the study?

It is your decision if you would like to know what I find out from the research. If you wish to know the results of the study, I can either provide you with a written summary of the study, or we can arrange a meeting where I can tell you the results.

What will happen to the results of the study?

I will share the results of the study with my supervisors. I will also write up the results of the study for submission as part of my training to be a Clinical Psychologist, and for publication in a scientific journal. These results will be entirely anonymous however, and no participants will be identifiable by name.

Who is organising the research and why?

I am training to be a Clinical Psychologist at the University of Edinburgh and work for NHS Tayside. I am carrying out this research as part of my training to become a Clinical Psychologist.

Who has reviewed the study?

The study proposal has been reviewed by the University of Edinburgh Doctorate in Clinical Psychology course and by my supervisors. NHS management approval and approval from the Scottish Dementia Clinical and Research Network have also been obtained.

The East of Scotland Research Ethics Committee REC 1, which has responsibility for scrutinising all proposals for medical research on humans in Tayside, has examined the proposal and has raised no objections from the point of view of medical ethics. It is a requirement that your records in this research, together with any relevant records, be made available for scrutiny by monitors from the University of Edinburgh and NHS Tayside, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

I want to know more about the study. What should I do?

If you wish to take part, or would like to meet with me to talk more about the study, please fill in your name and phone number on Consent Form 1 and we can arrange a time and place to meet to discuss the study further or to start the research. You can also phone to talk to me about the study. **My phone number is: 01356 692 806.**

I don't agree with the study. What should I do?

If you believe that you have been harmed in any way by taking part in this study, you have the right to pursue a complaint and seek any resulting compensation through the University of Edinburgh who are acting as the research sponsor.

Details about this are available from the research team.

Also, as a patient of the NHS, you have the right to pursue a complaint through the usual NHS process. To do so, you can submit a written complaint to the Patient Liaison Manager, Complaints Office, Ninewells Hospital, Dundee, DD1 9SY (Freephone: 0800 027 5507).

Note that the NHS has no legal liability for non-negligent harm. However, if you are harmed and this is due to someone's negligence, you may have grounds for a legal action against NHS Tayside but you may have to pay your legal expenses.

If you don't agree with any part of this study, you can also speak to:

My supervisor: Dr Fiona Macleod, Consultant Clinical Psychologist,
Susan Carnegie Centre, Stracathro Hospital,
By Brechin, DD9 7QA
Phone: 01356 692 806

Or talk to an independent NHS advisor:
Dr. Claire Campbell, Clinical Psychologist
NHS Tayside - Dundee Psychological Therapies
Carseview, 4 Tom McDonald Avenue, Dundee,
DD2 1NH
Phone: 01382 346055

Thank you for taking the time to read this information sheet and considering whether you would like to participate in this research.

If you wish to take part in the study, please sign the attached consent form and send it back in the self-addressed stamped envelope.

This information sheet is for you to keep.

Appendix B10: Participant Consent Form 1

Similarities and Differences in the Experiences of People with Dementia and their Partners
Consent Form 1 Version 5, 28/08/2013 Participant Code: _____



Similarities and Differences in the Experiences of People with Dementia and their Partners

Participants' Consent Form 1

Please complete this form and return it in the self-addressed stamped envelope included if you would like to meet with Rebecca Slade to discuss and/or begin the study.

☐

I agree to meet with Rebecca Slade to discuss participation in the study
(please initial this box if you agree with the statement)

Name: _____

Telephone Number: _____

Date: _____

Name: _____

Telephone Number: _____

Date: _____

Appendix B11: Participant Consent Form 2 – Scottish Dementia Clinical Research Network (SDCRN) Recruitment Pathway

Similarities and Differences in the Experiences of People with Dementia and their Partners
Consent Form 2 Version 6, 29/10/2013 Participant Code: _____



Similarities and Differences in the Experiences of People with Dementia and their Partners

Participant Consent Form

(Please initial each box if you agree with the statement)

| | |
|---|--------------------------|
| I have read and understood the Participant Information Sheet (Version 6, 19/06/2013) | <input type="checkbox"/> |
| I have had a chance to talk to someone about the study. | <input type="checkbox"/> |
| I know that I do not have to take part in this study and that I can stop at any time. I will not have to tell anyone why I want to leave the study. | <input type="checkbox"/> |
| I know that taking/not taking part in this study will not affect the care I receive from any services, either presently or in the future. | <input type="checkbox"/> |
| I understand that this study involves meeting with Rebecca up to a further two times. | <input type="checkbox"/> |
| I know that if I say something about myself or other people being at risk, this will be passed on to someone else (i.e. my GP). | <input type="checkbox"/> |
| I understand that my family doctor (GP) will be notified about my participation in this study. | <input type="checkbox"/> |
| I understand that all information given by me in this study will remain confidential. | <input type="checkbox"/> |
| I understand that relevant sections of data collected during the study may be looked at by the study researchers and individuals from the Sponsors (University of Edinburgh) and NHS Tayside where it is relevant to my taking part in this research. I give permission to these individuals to have access to my data. | <input type="checkbox"/> |

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Similarities and Differences in the Experiences of People with
Dementia and their Partners

☐

I agree to take part in this study
(please initial this box)

Participant Name: _____

Signature: _____

Date: _____

Witness Name: _____

Signature: _____

Date: _____

Name of Person Taking Consent: _____

Signature: _____

Date: _____

Appendix B12: Participant Consent Form 2 – NHS Tayside Community Mental Health Teams (CMHTs) Recruitment Pathway

Similarities and Differences in the Experiences of People with Dementia and their Partners
Consent Form 2 (Angus) Version 1, 31/10/2013 Participant Code: _____



Similarities and Differences in the Experiences of People with
Dementia and their Partners

Participant Consent Form

(Please initial each box if you agree with the statement)

I have read and understood the Participant Information Sheet (Angus)
(Version 1, 31/10/2013)

☐

I have had a chance to talk to someone about the study.

☐

I know that I do not have to take part in this study and that I can stop at
any time. I will not have to tell anyone why I want to leave the study.

☐

I know that taking/not taking part in this study will not affect the
care I receive from any services, either presently or in the future.

☐

I understand that this study involves meeting with Rebecca up to
a further two times.

☐

I know that if I say something about myself or other people being
at risk, this will be passed on to someone else (i.e. my GP).

☐

I understand that my family doctor (GP) will be notified about my
participation in this study.

☐

I understand that all information given by me in this study will
remain confidential.

☐

I understand that Rebecca will request the date and score of my most
recent cognitive assessment (ACE-III) from my clinician.

☐

I understand that relevant sections of data collected during the study
may be looked at by the study researchers and individuals from the
Sponsors (University of Edinburgh) and NHS Tayside where it is relevant
to my taking part in this research. I give permission to these individuals
to have access to my data.

☐

Page 1 of 2



Similarities and Differences in the Experiences of People with
Dementia and their Partners

☐

I agree to take part in this study
(please initial this box)

Participant Name: _____

Signature: _____

Date: _____

Witness Name: _____

Signature: _____

Date: _____

Name of Person Taking Consent: _____

Signature: _____

Date: _____

Appendix B13: Letter to GP of Participants

Similarities and Differences in the Experiences of People with Dementia and their Partners
GP Letter Version 3, 04/01/2013



NHS Tayside Older People Psychological
Therapies Service,
Susan Carnegie Centre,
Stracathro Hospital,
By Brechin, DD9 7QA

Date:

Enquiries to: Rebecca Slade
Direct Line: 01356 692 806
Email: rebeccaslade@nhs.net

«GP_Name»
«GP_Practice»
«Gp_Address»
«Gp_Address1»
«Gp_Address2»
«Gp_Address3»

Dear «GP_Name»

RE: «Name», «Address», «Town», «Area», «Postcode»

I am writing to inform you that «Name» agreed to participate in my research study which looks at similarities and differences in the experiences of people with dementia and their partners. This study is conducted as part of the Doctorate in Clinical Psychology at the University of Edinburgh and has been approved by the East of Scotland Research Ethics Committee on 25/03/2013. «Name» were initially approached «Recruitment».

The research requires participants to complete a series of mood and neuropsychological measures. Participants are offered breaks throughout in order to minimise fatigue.

If you wish any further information about the present study, please do not hesitate to contact me.

Yours sincerely,

Rebecca Slade
Trainee Clinical Psychologist

Appendix B14: Demographics Questionnaires

Similarities and Differences in the Experiences of People with Dementia and their Partners
Demographics Questionnaire Version 5, 29/10/2013 Participant Code: _____

Demographic Questionnaire

Demographics Questionnaire for Individual with Dementia: The Chief Investigator will be asking the questions to the participants and recording their responses below.

| | |
|---|-----------------------|
| Participant Code | e.g. S1001D or S1001P |
| Postcode | |
| Gender | |
| Date of Birth | |
| GP (Name, Address) | |
| Previous ACE-III Score and Date (if available) | |
| Diagnosis What is the diagnosis? When was the diagnosis given? By who? | |
| Occupational History At what age did you leave full time education? Are you working? Retired? (If so: When did you retire? What was your occupation?) | |
| Quality of life On a scale from 1 to 10 (where 1 = not at all satisfied and 10 = very satisfied), how satisfied are you with your life? This is better/worse/the same compared to 1 year ago? | |

| | |
|--|--|
| Medical History Do you have any physical health difficulties? Any traumatic brain injuries in the past? Any current medication and duration? | |
| Mental Health History Have you had any difficulties with your mental health in the past? | |
| Smoking/Alcohol Use | |
| Any additional information | |
| Would you like to be informed about the results of the study? If so: would you prefer this to be in written or verbal form? | |

Demographic Questionnaire

Demographics Questionnaire for Partner of the Individual with Dementia: The Chief Investigator will be asking the questions to the participants and recording their responses below.

| | |
|--|-----------------------|
| Participant Code | e.g. S1001D or S1001P |
| Postcode | |
| Gender | |
| Date of Birth | |
| GP (Name, Address) | |
| Occupational History At what age did you leave full time education? Are you working? Retired? (If so: When did you retire? What was your occupation?) | |
| Marital Status Married/ divorced/ single/ separated / living with someone? How long have you been together? | |
| Respite and Support How many days or relief do you have per week? What support do you receive from family, friends and/or professional carers? | |

| | |
|---|--|
| <p>Quality of life</p> <p>On a scale from 1 to 10 (where 1 = not at all satisfied and 10 = very satisfied), how satisfied are you with your life?</p> <p>This is better/worse/the same compared to 1 year ago?</p> | |
| <p>Medical History</p> <p>Do you have any physical health difficulties?</p> <p>Any traumatic brain injuries in the past?</p> <p>Are you currently on any medication?</p> | |
| <p>Mental Health History</p> <p>Have you had any difficulties with your mental health in the past?</p> | |
| <p>Smoking/Alcohol Use</p> | |
| <p>Any additional information</p> | |
| <p>Would you like to be informed about the results of the study?</p> <p>If so: would you prefer this to be in written or verbal form?</p> | |

Appendix B15: Hospital Anxiety and Depression Scale

Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) was not included due to copyright laws.

Appendix B16: Suffering Scales (For the Individual with Dementia)

Similarities and Differences in the Experiences of People with Dementia and their Partners
Experiences Questionnaire (For Individual with Dementia) Version 3, 04/01/2013

Participant Code: _____

Experiences of Dementia

I want to ask you some questions about how you have been feeling over the past week. Please indicate (a) how often you experienced each of the following symptoms during the past 7 days and (b) how much each symptom has bothered or distressed you.

| How often did you experience the following symptoms? | | | | |
|---|------------|-------------------------------|---------------------------------|---------------------------|
| Lack of energy/fatigue | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Lack of appetite | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Pain | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Dry Mouth | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Shortness of breath | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Nausea | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Difficulty Sleeping | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Constipation / Diarrhea | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Confusion / Difficulty concentrating | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |

Page 1 of 4

| Please indicate how often you experienced the emotions listed below during the <u>past 7 days</u> . How often did you experience the following emotions? | | | | |
|---|------------|-------------------------------|---------------------------------|---------------------------|
| Afraid | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Confident | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Worried or anxious | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Irritable | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Depressed | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Cheerful | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Hopeless | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Sad, blue | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Burden to others | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Angry | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |

| | | | | |
|-----------------------------------|------------|-------------------------------|---------------------------------|---------------------------|
| Lonely | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Embarrassed about yourself | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Guilty | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Abandoned | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Rejected | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |

| Please indicate how true each statement has been for you during the past 7 days. | | | | | |
|---|------------|----------|----------|-------------|-----------|
| I felt peaceful | Not at all | A little | Somewhat | Quite a bit | Very much |
| I had a reason for living | Not at all | A little | Somewhat | Quite a bit | Very much |
| My life had been a failure | Not at all | A little | Somewhat | Quite a bit | Very much |
| I had trouble feeling peace of mind | Not at all | A little | Somewhat | Quite a bit | Very much |
| I felt a sense of purpose in my life | Not at all | A little | Somewhat | Quite a bit | Very much |
| I felt a sense of harmony within myself | Not at all | A little | Somewhat | Quite a bit | Very much |
| My life lacked meaning and purpose | Not at all | A little | Somewhat | Quite a bit | Very much |
| I know that whatever happens with my illness, things will be okay | Not at all | A little | Somewhat | Quite a bit | Very much |
| Life was not worth living any more | Not at all | A little | Somewhat | Quite a bit | Very much |

Appendix B17: Suffering Scales (For the Partner of the Individual with Dementia)

Similarities and Differences in the Experiences of People with Dementia and their Partners
Experiences Questionnaire (For the Partner) Version 3, 04/01/2013

Participant Code: _____

Experiences of Dementia

I want to ask you some questions about how your partner has been feeling over the past week. Please indicate (a) how often your partner experienced each of the following symptoms during the past 7 days and (b) how much each symptom bothered or distressed your partner.

| How often did your partner experience the following symptoms? | | | | |
|--|------------|-------------------------------|---------------------------------|---------------------------|
| Lack of energy/fatigue | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Lack of appetite | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Pain | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Dry Mouth | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Shortness of breath | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Nausea | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Difficulty Sleeping | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Constipation / Diarrhea | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Confusion / Difficulty concentrating | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |

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| Please indicate how often your partner experienced the emotions listed below during the <u>past 7 days</u> . How often did your partner experience the following emotions? | | | | |
|---|------------|-------------------------------|---------------------------------|---------------------------|
| Afraid | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Confident | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Worried or anxious | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Irritable | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Depressed | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Cheerful | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Hopeless | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Sad, blue | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Burden to others | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Angry | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |

| | | | | |
|--------------------|------------|-------------------------------|---------------------------------|---------------------------|
| Lonely | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Embarrassed | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Guilty | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Abandoned | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |
| Rejected | Not at all | A little (A few days, 1-3) | Quite a bit (Most days, 4-6) | Very often (every day) |

| Please indicate how true each statement has been for your partner during the past 7 days. | | | | | |
|--|------------|----------|----------|-------------|-----------|
| He/she felt peaceful | Not at all | A little | Somewhat | Quite a bit | Very much |
| He/she had a reason for living | Not at all | A little | Somewhat | Quite a bit | Very much |
| His/her life had been a failure | Not at all | A little | Somewhat | Quite a bit | Very much |
| He/she had trouble feeling peace of mind | Not at all | A little | Somewhat | Quite a bit | Very much |
| He/she felt a sense of purpose in his/her life | Not at all | A little | Somewhat | Quite a bit | Very much |
| He/she felt a sense of harmony within himself/herself | Not at all | A little | Somewhat | Quite a bit | Very much |
| His/her life lacked meaning and purpose | Not at all | A little | Somewhat | Quite a bit | Very much |
| He/she knew that whatever happens with his/her illness, things will be okay | Not at all | A little | Somewhat | Quite a bit | Very much |
| Life was not worth living any more | Not at all | A little | Somewhat | Quite a bit | Very much |

Appendix B18: Scoring Guide for the Suffering Scales

Physical Symptoms

| Symptoms | Not at all | A Little (a few days, 1–3) | Quite a bit (most days, 4–6) | Very often (every day) |
|--------------------------------------|------------|----------------------------------|------------------------------------|---------------------------|
| Lack of energy / Fatigue | 0 | 0 | 1 | 1 |
| Lack of appetite | 0 | 0 | 1 | 1 |
| Pain | 0 | 0 | 1 | 1 |
| Dry Mouth | 0 | 0 | 1 | 1 |
| Shortness of Breath | 0 | 0 | 1 | 1 |
| Nausea | 0 | 0 | 1 | 1 |
| Difficulty Sleeping | 0 | 0 | 1 | 1 |
| Constipation / Diarrhea | 0 | 0 | 1 | 1 |
| Confusion / Difficulty Concentrating | 0 | 0 | 1 | 1 |

Psychological Symptoms

| Emotions | Not at all | A Little (a few days, 1–3) | Quite a bit (most days, 4–6) | Very often (every day) |
|----------------------------|------------|----------------------------------|------------------------------------|---------------------------|
| Afraid | 0 | 1 | 2 | 3 |
| * Confident | 3 | 2 | 1 | 0 |
| Worried or anxious | 0 | 1 | 2 | 3 |
| Irritable | 0 | 1 | 2 | 3 |
| Depressed | 0 | 1 | 2 | 3 |
| * Cheerful | 3 | 2 | 1 | 0 |
| Hopeless | 0 | 1 | 2 | 3 |
| Sad, blue | 0 | 1 | 2 | 3 |
| Burden to others | 0 | 1 | 2 | 3 |
| Angry | 0 | 1 | 2 | 3 |
| Lonely | 0 | 1 | 2 | 3 |
| Embarrassed about yourself | 0 | 1 | 2 | 3 |
| Guilty | 0 | 1 | 2 | 3 |
| Abandoned | 0 | 1 | 2 | 3 |
| Rejected | 0 | 1 | 2 | 3 |

Existential Symptoms

| Statements | Not at all | A Little (a few days, 1–3) | Quite a bit (most days, 4–6) | Very often (every day) |
|---|---------------|----------------------------------|------------------------------------|---------------------------|
| * I felt peaceful | 3 | 2 | 1 | 0 |
| * I had a reason for living | 3 | 2 | 1 | 0 |
| My life had been a failure | 0 | 1 | 2 | 3 |
| I had trouble feeling peace of mind | 0 | 1 | 2 | 3 |
| s* I felt a sense of purpose in my life | 3 | 2 | 1 | 0 |
| * I felt a sense of harmony within myself | 3 | 2 | 1 | 0 |
| My life lacked meaning and purpose | 0 | 1 | 2 | 3 |
| *I know that whatever happens with my illness, things will be okay | 3 | 2 | 1 | 0 |
| Life was not worth living anymore | 0 | 1 | 2 | 3 |

*Positive items – reversed coding for summed total scores.

Appendix B19: Interpersonal Reactivity Index

Similarities and Differences in the Experiences of People with Dementia and their Partners
Interpersonal Reactivity Index Version 3, 04/01/2013

Participant Code: _____

Interpersonal Reactivity Index

The following statements inquire about your thoughts and feelings in a variety of situations. For each item, indicate how well it describes you by choosing the appropriate number on the scale.

| Read each item carefully before responding. Answer as honestly as you can. Thank you! | | | | | |
|--|--------------------------------|---|---|---|-----------------------------|
| I daydream and fantasise, with some regularity, about things that might happen to me. | 0 Does not describe me well | 1 | 2 | 3 | 4 Describes me very well |
| I often have tender, concerned feelings for people less fortunate than me. | 0 Does not describe me well | 1 | 2 | 3 | 4 Describes me very well |
| I sometimes find it difficult to see things from the “other guy's” point of view. | 0 Does not describe me well | 1 | 2 | 3 | 4 Describes me very well |
| Sometimes I don't feel very sorry for other people when they are having problems. | 0 Does not describe me well | 1 | 2 | 3 | 4 Describes me very well |
| I really get involved with the feelings of the characters in a novel. | 0 Does not describe me well | 1 | 2 | 3 | 4 Describes me very well |
| In emergency situations, I feel apprehensive and ill-at-ease. | 0 Does not describe me well | 1 | 2 | 3 | 4 Describes me very well |

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| | | | | | |
|--|--------------------------------|---|---|---|-----------------------------|
| I am usually objective when I watch a movie/film or play, and I don't often get completely caught up in it. | 0 Does not describe me well | 1 | 2 | 3 | 4 Describes me very well |
| I try to look at everybody's side of a disagreement before I make a decision. | 0 Does not describe me well | 1 | 2 | 3 | 4 Describes me very well |
| When I see someone being taken advantage of, I feel kind of protective towards them. | 0 Does not describe me well | 1 | 2 | 3 | 4 Describes me very well |
| I sometimes feel helpless when I am in the middle of a very emotional situation. | 0 Does not describe me well | 1 | 2 | 3 | 4 Describes me very well |
| I sometimes try to understand my friends better by imagining how things look from their perspective. | 0 Does not describe me well | 1 | 2 | 3 | 4 Describes me very well |
| Becoming extremely involved in a good book or movie/film is somewhat rare for me. | 0 Does not describe me well | 1 | 2 | 3 | 4 Describes me very well |
| When I see someone get hurt, I tend to remain calm. | 0 Does not describe me well | 1 | 2 | 3 | 4 Describes me very well |

| | | | | | |
|--|--------------------------------|---|---|---|-----------------------------|
| Other people's misfortunes do not usually disturb me a great deal. | 0 Does not describe me well | 1 | 2 | 3 | 4 Describes me very well |
| If I'm sure I'm right about something, I don't waste much time listening to other people's arguments. | 0 Does not describe me well | 1 | 2 | 3 | 4 Describes me very well |
| After seeing a play or movie/film, I have felt as though I were one of the characters. | 0 Does not describe me well | 1 | 2 | 3 | 4 Describes me very well |
| Being in a tense emotional situation scares me. | 0 Does not describe me well | 1 | 2 | 3 | 4 Describes me very well |
| When I see someone being treated unfairly, I sometimes don't feel very much pity for them. | 0 Does not describe me well | 1 | 2 | 3 | 4 Describes me very well |
| I am usually pretty effective in dealing with emergencies. | 0 Does not describe me well | 1 | 2 | 3 | 4 Describes me very well |
| I am often quite touched by things that I see happen. | 0 Does not describe me well | 1 | 2 | 3 | 4 Describes me very well |

| | | | | | |
|--|--------------------------------|---|---|---|-----------------------------|
| I believe that there are two sides to every question and try to look at them both. | 0 Does not describe me well | 1 | 2 | 3 | 4 Describes me very well |
| I would describe myself as a pretty soft-hearted person. | 0 Does not describe me well | 1 | 2 | 3 | 4 Describes me very well |
| When I watch a good movie/film, I can very easily put myself in the place of a leading character. | 0 Does not describe me well | 1 | 2 | 3 | 4 Describes me very well |
| I tend to lose control during emergencies. | 0 Does not describe me well | 1 | 2 | 3 | 4 Describes me very well |
| When I'm upset at someone, I usually try to "put myself in his shoes" for a while. | 0 Does not describe me well | 1 | 2 | 3 | 4 Describes me very well |
| When I am reading an interesting story or novel, I imagine how <u>I</u> would feel if the events in the story were happening to me. | 0 Does not describe me well | 1 | 2 | 3 | 4 Describes me very well |
| When I see someone who badly needs help in an emergency, I go to pieces. | 0 Does not describe me well | 1 | 2 | 3 | 4 Describes me very well |

| | | | | | |
|---|-----------------------------------|---|---|---|--------------------------------|
| Before criticising somebody, I try to imagine how I would feel if I were in their place. | 0 Does not describe me well | 1 | 2 | 3 | 4 Describes me very well |
|---|-----------------------------------|---|---|---|--------------------------------|

Appendix B20: Caregiver Satisfaction Scale

Similarities and Differences in the Experiences of People with Dementia and their Partners
Satisfaction Scale Version 3, 04/01/2013

Participant Code: _____

Satisfaction Scale

| I would like to talk about some feelings you may be having. Please tell me whether you: Agree a lot, agree a little, neither, disagree a little or disagree a lot. | | | | | |
|---|------------------|---------------------|--------------|------------------------|---------------------|
| I get a sense of satisfaction from helping my partner | 5 Agree a lot | 4 Agree a little | 3 Neither | 2 Disagree a little | 1 Disagree a lot |

| Tell me how often you feel each way: | | | | | |
|---|--------------------|-----------------------|----------------|-------------|------------|
| How often do you feel that helping your partner has made you feel closer to him/her? | 5 Nearly always | 4 Quite frequently | 3 Sometimes | 2 Rarely | 1 Never |
| How often do you feel that you really enjoy being with your partner? | 5 Nearly always | 4 Quite frequently | 3 Sometimes | 2 Rarely | 1 Never |
| How often do you feel that taking responsibility for your partner gives a boost to your self-esteem? | 5 Nearly always | 4 Quite frequently | 3 Sometimes | 2 Rarely | 1 Never |
| How often do you feel that your partner's pleasure over some little thing gives you pleasure? | 5 Nearly always | 4 Quite frequently | 3 Sometimes | 2 Rarely | 1 Never |
| How often do you feel that caring for your partner gives more meaning to your life? | 5 Nearly always | 4 Quite frequently | 3 Sometimes | 2 Rarely | 1 Never |